EFFECTIVENESS OF AN INTEGRATED MODEL OF COMMUNITY BASED REHABILITATION ON THE QUALITY OF LIFE OF PEOPLE WITH DISABILITIES RESIDING IN URBAN SLUMS SOUTH INDIA

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ABSTRACT

Disability has a profound impact on a person's quality of life (QOL). Rehabilitation, a process by which measures are taken to improve the QOL of people with disability (PWD) uses several approaches. Community Based Rehabilitation (CBR) is one such approach, which evolved because of the magnitude of the problems of PWD in the community, the limited availability and poor access of rehabilitation services.

Research in CBR is limited and hence there is lack of evidence on outcomes in CBR. Considering the need for more information on current practice and research in CBR, the researcher studied the effectiveness of an integrated model of CBR set up in the Christian Medical College, Vellore, South India (VCBR). The objectives of this study were to generate theory on the value of an 'integrated model' that uses an educational strategy and to explore the value of secondary and tertiary care services for PWD in a community based rehabilitation programme for the improvement of their quality of life.

A 'Case Study' design was used. The practitioner role of the researcher added an important component to this study. An in depth study of 20 PWD, their immediate family members, concerned trained volunteers (LS) and others who were involved in VCBR was undertaken in addition to observation and reference of documents. Qualitative Analysis was undertaken based on the Framework Technique. The quality of life of PWD and the role of secondary and tertiary care centres in VCBR were studied.

In this study the realist approach, which takes note of the contextual elements in the evaluation of case study materials, showed that overall QOL of PWD will not improve to its full potential if solutions are mooted from polarized viewpoints. The study found that an integrated model of CBR that uses an educational strategy, has good links with secondary/tertiary care centres and makes use of social network/capital, which is available in the community, improved the overall QOL of PWD.

TABLE OF CONTENTS

APPENDICES

ACKNOWLEDGEMENT

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DECLARATION

I declare that the work contained in this thesis has not been submitted for any other award and that it is all my own work. This work was done in collaboration with the Christian Medical College, Vellore, India and was financially supported by the The Humane Research Trust, UK.

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CHAPTER 1 INTRODUCTION

1.1 Introduction

This thesis is about an integrated model of Community Based Rehabilitation (CBR) and how it impacted on the quality of life of people with disabilities. This study was undertaken as part of a Community Based Rehabilitation project in the slums of Vellore Town, South India, which will be referred to as VCBR from now on. The aim of VCBR which covered a population of 23,000 was to improve the quality of life (QOL) of people with disability (PWD), their families and communities, using an 'Integrated model', a key component of which was the transfer of knowledge, skills and attitude to the volunteers from the community. VCBR used an integrated model (rather than purely medical or social), that functions in the context of overall development using medical, physical, psychological, educational, social, vocational and recreational strategies as needed. Trained community volunteers identify and address the needs and problems of PWD. They continue to remain in their communities as a resource for PWD, their families and the wider community.

Research activity in Community Based Rehabilitation (CBR) is not well established and where it occurs has been limited and fragmented (Wirz, 1996). There is however abundant potential for research in CBR, which spans many areas like service delivery, use of volunteers, community participation and many others. It can also be used to enhance growth and development in CBR. This study was undertaken to evaluate the effectiveness of an integrated model of CBR in improving the quality of life (QOL) of PWD.

1.2 Background

An estimated 10% of the world's population - approximately 600 million people, of which 200 million are children - experience some form of physical, mental, or intellectual disability. The most common causes of disability include chronic conditions such as cardiovascular, respiratory diseases, cancer, diabetes, mental illness, malnutrition, HIV/AIDS and other infectious diseases. Disability is also caused by injuries such as those due to road traffic crashes, falls, landmines and violence. The numbers of People With Disability (PWD) is growing as a result of factors such as population growth, ageing and medical advances that preserve and prolong life. These trends are creating considerable demands for health and rehabilitation services and require environmental and attitudinal changes. Poverty is a root cause of many disabilities and disability increases poverty further. About 80% of the PWD in the world live in low-income countries, often in poverty, isolation and despair. Poverty further limits access to basic health services, including rehabilitation and education. Most developmental initiatives ignore the needs of people with disabilities (WHO, May 2005).

In India, enumerating the number of PWD was part of the census from 1881 to 1931. The enumeration of PWD however was not the primary focus of the census. The orientation and training of enumerators probably did not give priority to this area of data collection leading to consistently low prevalence data for disability in the country. Since the returns were not satisfactory (less than 0.4%) the Census Commissioner discontinued disability related enumeration from 1941 to 1971. 1981 being the International year of disabled people saw enumeration of PWD returned to the census which showed a prevalence of 0.2%. Disability enumeration was discontinued subsequently till following campaigning by activists and politicians it was included in the census of 2001 (Tamhane, 2002). Training of enumerators and wide publicity preceded the enumeration. This census returned a figure of 2.3% (Registrar General & Census Commissioner India, 2001) which although greater than previous years

was less than the expected. The National Sample Survey Organization (NSSO) estimated that 1.8% of the population are PWD (NSSO, December 2003).

In 2006, the statistics division of United Nations (DISTAT) carried out a study to determine the global prevalence of disability. They requested and received information based on surveys, censuses and administrative records from several countries. Data for India in this study which came from the 1981 census reported a prevalence of disability of 0.2%. Philippines reported data from 1995(1.3% prevalence), Egypt and New Zealand reported data from 1996 with a prevalence of 4.4% and 20.0% respectively. The study found that there was great variability in the reports from different countries with respect to year of survey/census, method of survey/census and the questions asked. The report therefore recommended that inter-country comparisons should not be done because of differences in the concepts and methods used to identify persons with disabilities (UN-DISTAT, 2006).

It is recognized that in many developing countries accurate data on prevalence of disability in a population is not available (Arne H Eide & Loeb, July 2005). The CBR Network commented, "Many ESCAP (Economic and Social Commission for Asia and Pacific Regions) developing and least developed countries and areas do not collect disability data. In the case of those that have done so, the data collected do not reflect the full extent of disability prevalence. This limitation is due in part to the conceptual framework adopted, the scope and coverage of the surveys undertaken, lack of standardization of definitions, classifications and the methodology used for disability data collection." They suggest that there is no authentic data on disability in India and estimate that PWD constitute 4-5% of Indian population (CBR Network, 2002, p.1-2).

Though there is considerable disagreement about the prevalence of disability, Helander in 1992 suggested that about 5% of the population actually needs rehabilitative services to improve the quality of their lives (Helander, 1992). WHO in the 1980's reported that 70% of disabled people could be rehabilitated within the community, while the remaining 30% comprising of people with

severe and multiple disabilities require more specialist interventions (WHO, 1981).

Accessible rehabilitative services in India as in other developing countries are poor. The common impediments are

- ✓ Lack of knowledge about rehabilitation
- ✓ Poor affordability and accessibility of services
- ✓ Non-availability of trained personnel
- ✓ Poor utilization of available services and benefits

The challenge for rehabilitation professionals, PWD, their families and communities is to evolve and validate strategies that can be utilized to address the need for rehabilitation of disabled people in the community. Community based rehabilitation (CBR) is an attractive solution since existing resources have failed to address rehabilitation needs.

1.3 Trends in Rehabilitation

In India, institutionalized rehabilitation was practiced in early days of the 20th century. PWD were given food, shelter, education and vocational training in special institutions. However this meant that they were secluded from the social mainstream. Later Institution Based Rehabilitation came into existence, where the PWD were provided with rehabilitation services at an institution with the goal of preparing them to return to their homes and join the social mainstream.

Some of the Institution Based Rehabilitation programmes (IBR) realised the importance of considering the environment of the individual in the process of rehabilitation, and hence community oriented rehabilitation developed as a logical next step. Through the collection of information on the environment from individual clients or by home visits wherever possible, experience in community oriented rehabilitation developed. This enabled appropriate goal setting for an individual's rehabilitation programme in the institution.

The range of disabilities identified in the training manual for CBR workers (Helander, Mendis, Nelson, & Goerdt, 1989), are:

People who have difficulty seeing
People who have difficulty speaking and hearing
People who have difficulty moving
People who have no feeling in the hands or feet
People who show strange behaviour
People who have fits
People who have difficulty learning

Although this categorization does not differentiate the severity of the disability, in each of these categories mild, moderate and severe forms of the disability will be present. Those with severe disability and or specific conditions will certainly need Institution Based Rehabilitation in a secondary or tertiary care setting. Many people with disabilities that are mild or moderate (not severe) will benefit from the services of a good rehabilitation centre (IBR). However these institutions are few and located mainly in the cities. They are expensive and many people are not aware of their existence or of the possibility of these rehabilitation options. These centres are therefore inaccessible in terms of cost, awareness and distance and only a small percentage of PWD actually use such services. Factors preventing access to these services are thought to include the financial cost and the time taken to visit the hospital, but other issues may also be significant (Kassah, 1998).

Recognizing this need, the World Health Organization (WHO) deliberated on an alternative approach to rehabilitation of PWD about twenty-five years ago (WHO, 2005). In accordance with the principles of Primary Health Care following the Declaration of Alma Ata in 1978, CBR emerged as a new concept in rehabilitation. CBR was one of the components of the primary health care system but the priority given to it was low when compared to other components (Mohale & Miles, 1998).

CBR is one of the approaches in the field of rehabilitation of PWD, which evolved because of the magnitude of the problems of PWD in the community

and the limited availability of rehabilitation resources. This approach, therefore, seeks to address the problems of the majority of PWD in the community itself. While it is envisaged that most of the interventions will take place in the community, some interventions are not possible within the community setting; hence many CBR programmes are linked up with relevant institutions for referrals - for example, cataract surgery is best undertaken in a tertiary setting.

1.4 Understanding CBR

In the beginning, rehabilitation that took place in the community was defined as CBR as opposed to rehabilitation that took place in the institution. With experience, it was recognized that community participation and utilization of local resources are also important components of CBR. In recent years, CBR is seen as a community development issue rather than an individual's disability issue. It is interesting to look back on how this approach has emerged in the field of rehabilitation and what are the different strategies adopted in CBR over the period of time.

Although CBR was earlier defined as the delivery of rehabilitation therapy to PWD in the community, defining CBR today is not an easy task. The difficulty arises from the complexity of CBR, which is the result of the current concept that CBR programmes should be multi-sectoral so that they can provide assistance in all the areas that are central to improvement of the quality of life of people with disabilities. This complexity recognizes the need for close coordination, collaboration and cooperation between different sectors of development (health, education, etc), governmental and non-governmental organizations of all types and at all levels.

In 2004, the WHO, ILO and UNESCO brought out a joint position paper on CBR. Their definition of CBR in this paper, which is now widely accepted, brings together these different aspects. (ILO, UNESCO, & WHO, 2004)

1.5 Global scenario

Initially, CBR was seen as an alternative service delivery approach for rural and marginalized areas not having access to services. With time and experience it has developed as an instrument for promoting empowerment of persons with disabilities and their families, for advocacy of human rights and for improving their access to resources and services (Pupulin & Deepak, 2002). CBR is being implemented in more than 90 countries and has evolved into an effective comprehensive multi-sectoral strategy in creating access to health care, education, livelihood opportunities and participation / inclusion (WHO, 2005).

The scope of CBR has grown based on local needs. The common ones are

- ✓ Using the community as the starting point
- ✓ Demystification of existing technology and knowledge
- ✓ Cross disability coverage
- ✓ Maximising benefit for the majority of PWD
- ✓ Widening community participation
- ✓ Networking of PWD
- ✓ Creating bonds between PWD and others in the community
- ✓ Flexibility that encourages the participation of other sectors
- ✓ Prevention of disability

Having realized the potential of CBR, many countries such as Australia (Kendall E, Buys N, & Larner J, 2000) , Cuba (Werner, 2004), Cambodia (Delneuville A, Bonnet J, Roath L, Jacobs H, & Dos S, 2000), Canada (Fricke M et al., 2004), Eritrea (Grut L, Hjort P, & Eide AE, 2004), India (Sudipto Chatterjee, Vikram Patel, Achira Chatterjee, & Helen A. Weiss, 2003), Kosovo (Turmusani, 2002), Nepal (AIFO, 2005), Palastine (Arne H. Eide, Harami, & Greer, 2005; Giacaman, 2001), Philippines (Lopez JM, Lewis JA, & Boldy DP, 2000), Uganda (Claussen J, Kandyomunda B, & Jareg P, 2005), UK (Powell, Heslin, & Greenwood, 2002), USA (Brekke JS & Long JD, 2000), Vietnam (Pierdomenico L, 2003) and Zimbabwe (Mpofu, 2001) have initiated CBR programmes. Changes in the social and political context of some of these

countries is likely to influence the sustainability of CBR programmes. There are many developing countries, which are not fully involved in implementing CBR. In India, in early 1995, the government launched the District Rehabilitation Centre (DRC) Scheme as a model of comprehensive rehabilitation services for the rural poor. There are 11 DRCs in India (GOI, 2004). These DRCs are functioning like pilot projects where the practice is based on the CBR approach. India being a large country with 593 districts (Registrar General & Census Commissioner India, 2001) experimenting with CBR in only 6% of the districts is just a small beginning. But there are many small-scale CBR programmes being operated in India by NGOs. From the researcher's experience of working in the field of rehabilitation for almost two decades, he suggests that the following may be some of the reasons for slow progress:

- ✓ Lack of understanding of concept
- ✓ Finance / Prioritization
- ✓ Poor planning / management of CBR
- ✓ Policies and expectation of funding agencies
- ✓ Expectation of immediate results
- ✓ Cost effective versus expensive
- ✓ Lack of coordination between government and NGOs
- ✓ Non-inclusion of disability as a cross cutting issue by government
- ✓ Threat to professionals

Though CBR was promoted to meet the needs of PWD in developing countries, the magic word "CBR" has gained importance in both developing and developed countries. Many developed countries had thought that CBR was meant for countries where resources are meagre (WHO, May 2005). In reality, CBR as practiced in developing countries has brought to light the possibilities for improving existing rehabilitation services in developed countries as well. The IDCC (International Disability and Development Consortium) is an association of international non-governmental agencies based in various European countries. Its aim is to promote the rights of PWD through the sharing of information and expertise. It welcomes the diversity of practice and wishes to acknowledge it and see it as a rich source to be learnt from (IDDC, October 2002).

1.6 Researcher's interest

The researcher has been stimulated by the current situation of CBR practice and is concerned about the following specific situations:

- ✓ Lack of enthusiasm in expanding CBR in needy countries like India
- ✓ Enthusiasm shown by developed countries in learning from developing countries about various approaches to rehabilitation
- ✓ The debate between the medical and social models of disability and rehabilitation
- ✓ The compartmentalized view of professionals regarding the needs and services for PWD
- ✓ Limitations of Institutions which offer rehabilitation (such as single disability focused; serving only the privileged; short term support)

The researcher believes that the lack of access to information is a primary barrier for PWD and other stakeholders in Rehabilitation. Sharing information is crucial to the development of CBR. Many people are engaged in good work but others never hear about it and the wheel is reinvented every time.

This field of CBR needs to grow with evidence. Currently, there are only a few evidence-based reports known to researchers and practitioners of CBR. Finkenflugel et al (2005) reviewed studies on CBR published between 1978 and 2002 to assess the evidence base for CBR. They reported that the research base for CBR was weak and there is an increasing number of publications on CBR based mainly on theory and less on the evaluation of interventions (practice). A similar study carried out by Wirz and Thomas (2002) in 2002 reviewed 10 published evaluation reports. They found that most of the reports described practice rather than impact. They have suggested some indicators which may be used for CBR practice evaluation. Other sources of information such as programme reports, newsletters and conference proceedings, which reflect practice situations, are not easily accessible. It would appear that we do not know what information is available, what the

quality and usability of that information is, and which aspects have been well covered or which should be a priority for further research (Hartley, 2006).

Considering the practice and research situation of CBR, this thesis is entitled "A study of the effectiveness of an integrated model of CBR on the quality of life of people with disabilities residing in urban slums, South India". This study will contribute to the practice of CBR through a *detailed* analysis of the practice development undertaken in this area. The model of an integrated service built on education and support of volunteers from the communities illustrates empowerment of PWD, the volunteers and these communities, and is explored through the concepts of social capital and social networks. The study will be reported both through the academic and practice literature in particular as "Guidelines based on experience" to reach grassroots practitioners. Mitchell (1999, p.1) says, "CBR and ultimately the disabled can only benefit from placing research and evaluation of CBR into the public domain".

1.7 Terminology

Many pejorative terms have been in common use to identify a person with disability in the more developed world and many are still used in developing countries. Acceptable terminology is specific and focuses upon the person, not upon the disability. It also avoids portraying the person as powerless. This terminology varies across the world. It is sensible to be guided by what is acceptable to local organisations of disabled. It should be noted that frequently, local language provides a clear insight into how disabled people are perceived in society. For example, in Rwanda, the personal prefix used for people is replaced by that used for a small inanimate object, so *umu-ntu* (a person) becomes *iki-muga* (a disabled person) or, literally, a broken, worthless piece of pot (Enfield, 2001). This type of terminology is common and insidious. In this thesis the author uses the term PWD (people/person with disability), which is officially used (GOI, 1996) and widely accepted in India (Evans, Zinkin, Harpham, & Chaudury, 2001).

CHAPTER 2 THE CONTEXT

2.1 Introduction

This chapter describes the integrated model of CBR within which the study was carried out. Since its purpose is to make clear the context within which the study was carried out, details of study methodology will not be described here but in Chapter 4. This chapter will focus on how VCBR was initiated, volunteers selected, PWD in slum communities reached, educative strategies used and how care pathways were set up for PWD.

Within this project the researcher played dual roles as practitioner and as researcher. As practitioner, he took on varied responsibilities as co-ordinator, facilitator, trainer, service provider, and counsellor, and as a bridge between the community and VCBR. The problems related to being a practitioner researcher are discussed in detail in chapter 4.

2.2 Geography

In India, there are 35 states in which people use 114 languages, of which 18 are scheduled and the rest are non-specified. India is one of the oldest civilizations on earth, with a kaleidoscopic variety of cultures and a rich heritage. It has achieved multifaceted socio-economic progress since independence. India has become self-sufficient in agricultural production and is now the tenth industrialized country in the world and the sixth nation to have gone into outer space. With a population of 1.029 billion, India is ranked 124 out of 173 on the Human Development Index (HDI), according to the UNDP Human Development Report (2002).

Four key indicators used to calculate the HDI: longevity, educational attainment and standard of living, show the following:

- ✓ Longevity, measured, as life expectancy at birth, was 62.8 years for men and 63.8 years for women
- ✓ Educational attainment, measured as the gross enrolment ratio, was 62 per cent among boys and 49 per cent among girls and
- ✓ Adult literacy rate was estimated to be 57 per cent with a higher rate (68.4 per cent) recorded for men than for women (45.4 per cent)
- ✓ Standard of living, measured as annual per capita GDP, was U.S $ 2,358 in 2000

Poverty remains a significant problem in India. Over a quarter of the population was living in poverty in 1999/2000 according to the Economic Survey 2001/2 carried out by the Ministry of Finance (International Labour Organization, 2003).

Tamil Nadu State has a population of 62 millionas per census 2001 and covers an area of 130,058 km^2. It is one the southern states of India where there are 30 districts and the administration of the state based mainly on rural and urban classification. Municipal administration is created for urban management, and panchayat raj administration is created for rural management.

Figure 2.1 showing map of districts in Tamil Nadu state

Error!

Vellore district lies between 12° 15' to 13° 15' North latitudes and 78° 20' to 79° 50' East longitudes in Tamilnadu State. The geographical area of this district is 6077 sq. km. The total population as per 2001 Census is 3.4 million (Registrar General & Census Commissioner India, 2001). Agriculture, tanneries and small-scale industries are the main sources of employment and income generation for the people of this district The outstanding performance of this district in contributing to the Military services, serving the nation with indomitable spirit and courage has been commended by the state government in its official website (Rajendran C, 2009).

Figure 2.2: Map of Vellore District

Vellore, the Headquarters of Vellore District, situated in 12' 35' N and 79' 9' E, has a very interesting history of its own. Vellore had the privilege of being the seat of the Pallava, Chola, Nayak, Maratha, Arcot Nawabs and Bijapur Sultan Kingdoms. It was described as the best and the strongest fortress in the Carnatic War in the 17th Century. The sepoy mutiny - a massacre of European soldiers in 1806, took place in Vellore Fort. (Viswanathan S, 2006). This town is blessed with some educational institutions, which are being run by the government, pubilc and NGOs. Vellore Town has a population of 177,413 and the area is 11 square kilometres (Registrar General & Census Commissioner India, 2001).

The Christian Medical College (CMC) is a teaching hospital, located in the heart of Vellore town. This missionary hospital was established in 1900 and has developed over the years into a super speciality treatment facility. It has an excellent reputation in health care, and patients from all parts of the country and neighbouring countries come seeking medical care and treatment (Bhupta, 2008; NAAC, 2009). During 2005-2006 1,434,057 outpatients and 92,248 inpatients received services from CMC. There were 5,911 personnel working in various cadres (CMC, 2005-2006). CMC has outreach services in two rural development blocks of the district and has an urban health centre, which is called the Low Cost Effective Care Unit (LCECU). The LCECU acts as the secondary care centre for the VCBR and services the poorer sections of Vellore Town.

The VCBR team consists of professionals from both the department of Physical Medicine and Rehabilitation (PMR) and the LCECU. The department of PMR offers comprehensive rehabilitative services to PWD, mainly for persons with spinal cord injury, brain injury, cerebral palsy, polio and amputation. This department conducts various rehabilitation related courses such asMD (PMR), Bachelor of Physiotherapy, Bachelor of Occupational Therapy, Diploma in Prosthetics and Orthotics. This department serves as a tertiary care centre especially for people with difficulty in moving. The Low Cost Effective Care Unit (LCECU) is one of the units of CMC, and is located in the centre of the town, close to the majority of the people in the VCBR coverage area. This unit offers both outpatient and inpatient services to poor people in Vellore Town. On an average, 200 patients attend outpatient services everyday. The bed strength of the unit is 46. This unit has a special feature of offering outpatient medical services at a concessional rate. (Rs.25/- is charged at the time of first registration and all the repeat registrations are free) The inpatient facility is free. The patients pay for the drugs at cost price, and are given full or concessional rates for the investigations. The unit has good support from the speciality departments of CMC. Apart from medical care, counselling support and physical/mental exercise group sessions are conducted once a week. This unit serves as the secondary care centre for the PWD from the community.

2.2 Vellore CBR (VCBR)

VCBR was a collaborative project between the department of Physical Medicine and Rehabilitation (tertiary care centre), the Low Cost Effective Care Unit (Secondary care centre) and the local community (slum areas of Vellore). The Department of Physical Medicine and Rehabilitation (Department of PMR) has expertise in dealing with PWD especially for those who have physical disabilities. The Low Cost Effective Care Unit (LCECU) has expertise in working with poor/vulnerable/marginalized communities from Vellore Town. With the financial support of World Health Organization (WHO), VCBR was initiated in 2002. This PhD study was funded by the Humane Research Trust, UK.

Integrated CBR services were provided by a team from all three levels (community, LCECU & Dept of PMR). Volunteers (Local Supervisors) from the community were the key people in VCBR. Through appropriate training, they were able to identify PWD, their needs and with the help of the team, provide integrated rehabilitation services. The facilities at the secondary and tertiary care centres were utilized as and when necessary, but the major parts of the rehabilitation services were provided in the community by the volunteers.

2.2.1 Objectives of VCBR

The aim of the Vellore CBR project (VCBR) was to evaluate whether the quality of life of PWD can be improved through integrated CBR services. This was achieved by:

- ✓ training volunteers from the community to identify PWD and their needs, and carry out basic interventions using local resources, including referral as appropriate;
- ✓ delivering an integrated service through these trained volunteers to PWD within their communities
- ✓ raising awareness within the communities of the needs, problems and abilities of PWD.

Within this larger project, this study aimed to find out the impact of this particular model of CBR on the lives of PWD including the significance of the secondary and tertiary care services.

2.2.2 Defining the Community or Area

In VCBR, poorer areas of the Vellore town (a population 23,000) were covered. The VCBR team made several visits to the community to engage community leaders prior to inviting willing areas to take part. Information from the Vellore Municipality regarding the slum population in Vellore town was collected. The slum population of Vellore town was 67,184. (VMH, 2002) The VCBR team also referred to the data generated by a household survey done in 1997 in Vellore Town by the Department of Biostatistics, CMC, Vellore. (Biostatistics department, 1998)

The VCBR coverage area (some of the poorer areas of Vellore Town) is very congested and the houses are located in narrow and uneven streets. Some of the houses are located at the bottom of a hill. Most of the people have constructed their houses on "porambokku land" (public property where the people have settled without registration of land). The people in this area are mostly employed in physical work, and their jobs largely depend on their physical strength. The work they do include loading and unloading work in the vegetable market, plying cycle rickshaws, making beedis, brooms, etc. Water scarcity is a major problem in this area. The Municipality supplies water once in 15 days during summer. Smoking and drinking alcohol are very common in this area. A needs assessment survey done by a team of community medicine practitioners of CMC in two slums of Vellore town found that access to safe water supply, sanitation facilities, and garbage disposal was very low. A sizeable proportion had inadequate access to high-quality antenatal and obstetric care (Mony P.K et al., 2006).

2.2.3 Entering into the community

Observational field visits to most backward areas in Vellore Town were done to make contacts and to have preliminary information about the community. Having established rapport with the community by regular visits and interaction with the formal, informal leaders and other members in the community, formal consultation meetings were conducted. 17 consultation meetings were conducted in public places at 15 areas over the period of 10 months from February 2002.

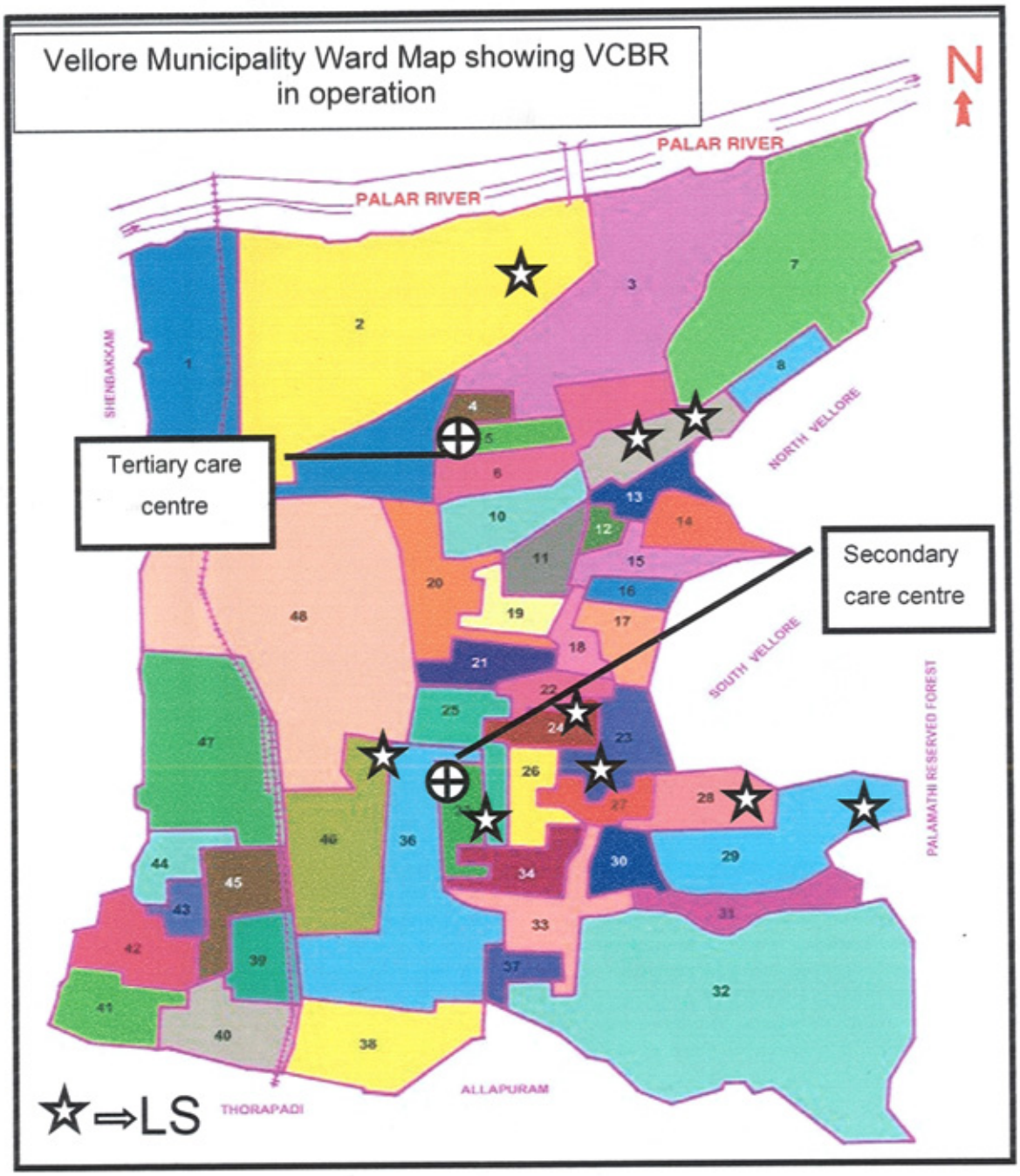
2.2.4 Selection of volunteers

Meetings were held in the slum communities of Vellore Town. Local leaders like the Municipal Counsellors, and Youth and Women representatives were involved in the meetings. In the first few communities where meetings were held, the VCBR staff visited each household and invited the people to attend the meeting. Subsequently Municipal Counsellors or other responsible persons in the community were assigned the responsibility of informing the community about the meeting. Handbills were circulated to ensure that many people were aware of the meeting. Sixty five people (7 male and 58 female) came forward to act as Local Supervisors (World Health Organization uses this term for the volunteers of CBR programme and now onwards the volunteers will be called as Local Supervisors and in short as LS). Through a process of interviews and clarification of the nature of the work of the LS in the project, ten were selected based on the following criteria:

- ✓ From the local community
- ✓ Able to read and write in local language.
- ✓ Have family support
- ✓ Have time to spare for community activities (2-3 hours a day)
- ✓ Have a positive attitude towards PWD and community development
- ✓ Have experience in dealing with disability or be disabled themselves

Of the ten selected, one volunteer felt unable to participate soon after selection. Since there was no other volunteer from this community, the leaders of this community were informed that we were unable to cover their area at the time through VCBR. (see Figure 2.3) These 9 LS were then trained to carry out the objectives of the project.

Figure 2.3: The area of operation of CBR in Vellore Town



2.3 Educational Strategy in VCBR

The VCBR followed an educational strategy within an integrated model, which aimed to make changes in three key components (Knowledge, Attitude and Practice) of various stakeholders such as LS, PWD, their family members, trainers (secondary and tertiary care centres) and the wider community. However it was the LS who were primary forcus for the traininig. They were able to pass on the knowledge, attitude and skills to PWD, their families, trainers and wider community. The trainers also conducted general awareness sessions in VCBR area.

In VCBR, the concept of learning incorporated three interrelated components:

1. the cognitive component (pertaining to the learning of content and subject matter related to disability and rehabilitation)
2. the affective component (pertaining to the learning of attitudes, values and feelings, and how to express these within one's cultural and social surroundings. Throughout the training programme the values of dignity and ability was stressed. The LS were trained to see the positive aspects of PWD)
3. the psycho-motor component (pertaining to the learning of specific skills including communication, organization and therapeutic skills) (Draper, 1995)

Transfer of knowledge and skills took place in both directions (from professionals to LS and vice versa; from LS to PWD and their families and vice versa), which confirmed a partnership-based teaching and learning resulting in a transformation of practice. For example while training the LS on 'how to identify people with difficulty seeing' the formal tests mentioned in the WHO manual (Helander et al., 1989) were explained. One of the LS suggested that picking stones from rice or threading a needle may also be used to test vision. Similar reciprocal teaching and learning also occurred at the community level. For example, while learning about 'how to make a person with difficulty seeing to be independent', three of the LS shared what they have learnt from PWD in their communities. By sharing what they had seen from each area they helped

others to learn. The sharing of expertise by professionals and practical knowledge by PWD/Family/LS resulted in collective learning where all members benefited.

2.3.1 Teaching-Learning

Lack of knowledge is one of the main barriers to accessing rehabilitation services. PWD and their family members need to acquire knowledge and skills to improve their QOL. In VCBR, the knowledge gap was reduced through the use of an educational strategy. Training of LS introduced knowledge into the community and informed the PWD and their families. The training of LS was carried out using the principles of adult learning, i.e. drawing on the LS need to know, allowing self direction, drawing on experience, using a problem solving approach and motivating the LS to learn (Knowles, Elwood F. Holton III, & Richard A. Swanson, 2005). For example, whilst undertaking a survey to identify people with various disabilities using the WHO guidelines, they came across individuals with multiple disabilities and some with chronic medical conditions. These conditions had not been included or classified in the training manual. The trainers and the trainees (LS) jointly framed an operational definition and classification for these conditions and relevant to their context. Because the teaching learning process was open to learner involvement, the learners were comfortable to raise questions/ problems /issues in the course of learning. For example, during the initial survey the LS encountered the problem of alcohol abuse, which created many problems for the individual and the family. Initially they felt that alcohol abuse should be listed as one of the disabling conditions and included as part of the survey. However they soon realized that this is also a culturally sensitive issue, which many people might not wish to disclose. They felt comfortable discussing this issue among themselves during the training sessions. They decided it was not appropriate to include alcohol abuse in the survey. However they felt that if either the person with the problem of alcohol abuse or any of his/her family approached one of them for care, this should be provided. As a result of this type of training, the LS were comfortable and confident in the day-to-day practice in the field. The trainees were encouraged to self-appraise and reflect on their performance. For

example, each of them was provided with a bar chart depicting their average monthly attendance for the training programme. This enabled some of the trainees who were less regular than others to understand and improve their attendance.

2.3.2 Training Resource and content

The WHO training manual for CBR (Tamil version) was used as a primary training resource (Helander et al., 1989). By using this training manual, the LS were helped to complete a survey to identify various disabling conditions and common problems faced by PWD (See Appendix 1, Form I). In addition to the WHO manual, the LS gained knowledge and skills from the expertise of trainers from variety of professional background (Occupational Therapists, Physio Therapists, Prosthetists and Orthotists, Social Workers, Doctors, Nurses & Psychologists). A very important component of their learning came from listening to and observing and working with PWD themselves. Exploring the felt needs of PWD and their families also led to the identification of areas not covered by the WHO manual. For example, the importance of communication, type of needs (felt needs, expressed needs and perceived needs), prioritization of needs, vocational options for PWD, prevention of backache while handling a PWD, immunization schedule, government schemes for the PWD, general health needs of the community, tuberculosis, diabetes, stroke, spinal cord injury, acquired brain injury. All these areas (and more) were topics identified for further learning by LS, PWD and their families and the trainers, which had not been covered by the training manual.

Almost all topics related to disability and rehabilitation were covered during training. In addition they were given training on various emerging problems in the community for example, 'community mental health'. They were also exposed to various other community-based programmes for PWD. Continuing education on need-based topics was found useful in enhancing the knowledge base and sustaining the interest of the LS in CBR. According to Sindhu Padke (Phadke, 1995), training of volunteers must be seen as a continuous process

and not a one shot effort aimed at upgrading their competence and enabling them to take on newer and more challenging tasks.

2.3.3 Need driven training

Using the WHO manual (Helander et al., 1989, p.38-40) (See Appendix 2, Form II) the LS conducted an assessment of needs of individual PWD. The needs and problems varied from physical, psychological, social, vocational and economic. The training for the LS was carried out based on the particular need/problem the LS had identified. During the course of their contact with individual PWD, the LS came to know about various problems of the PWD. These were discussed in the training sessions. For example, following training on 'how to make a person move around for a person having difficulty moving', one of the LS presented the problems of an old lady who had fractured her femur and had associated pain and a limp. The trainer noted these problems and expanded the training to cover the problem of correcting limb shortening even though this was not included in the training manual. This particular approach not only helped the LS who had raised the problem, but all the others as well. When they came across similar problems later, they were able to start intervention immediately. Thus needs driven, comprehensive, flexible training helped the LS to learn optimally for their context and they were able to provide appropriate intervention to the PWD.

2.3.4 Effect of training the LS

The need driven training helped the LS to provide appropriate intervention based on the needs and problems of PWD. The range of intervention included exercises, mobility training, training for independence, vocational guidance, psychological support, referral to secondary and tertiary care centres and to other institutions and follow-up / after care at secondary and tertiary care centres. SK's admission in a residential home is an example of appropriate intervention because of training of LS. Though the LS was aware of all the problems faced by SK, she was unable to suggest any intervention because of lack of knowledge. The training enabled her to consider several possible

options for the care of SK and she could take steps to address his problem. (Ref: SK's report in Appendix 4)

VN who had difficulty moving following an accident was taught exercises by the LS who also taught the same exercises to VN's wife. His mobility improved following the exercise regime for which he was helped by his wife. During her visit to one of their relatives, VN's wife taught these exercises to an old lady who had a similar problem. In her words,

> *"I taught her two or three exercise like sitting from standing (demonstrates), rotating the ankle while sitting and also advised her to do these exercises when she gets up. I also told her that it will help her to reduce the stiffness. There is no need to go to hospital"*

After she returned, VN's wife kept in touch with this person and found that her condition had improved. This ripple effect or multiplier effect was possible through the educational approach to CBR. Sharma and Deepak (Sharma & Deepak, 2003) suggests that if CBR projects provide educational activities that build self-efficacy of volunteers to fulfil CBR related tasks it would encourage retention of volunteers.

2.3.5 Training and the use of local resources

The already existing knowledge of the LS supplemented by additional skills and knowledge acquired from professionals helped the LS to use local resources to improve the QOL of PWD. The use of local resources is one of the principles of CBR (Helander et al., 1989). "CBR programmes globally have developed ingenious ways of utilising local resources – people, material and finances. Low cost aids and equipment can be produced from local material by local people and CBR programmes can empower disabled people and parents to take an active role in their communities and in CBR implementation" (IDDC, October 2002, p.3). The WHO recommended the use of volunteers to act as Local Supervisors in CBR (Helander et al., 1989). Thomas and Thomas (1998) emphasized the use of local resources in CBR and Werner (2002) specifically mentioned the use of local people in CBR. In VCBR, volunteers were identified and trained as LS. Once the LS were active within the communities, they in turn

demonstrated innovative use of local resources. For example, one LS with the help of local people put up a wooden parallel bar for AR and RA near their home, one used a coconut shell as a splint for VI's clawed hands, another suggested picking stones out of rice as an identification strategy for difficulty in seeing. Training helped the LS to use local resources innovatively to improve the QOL of PWD.

2.3.6 Training and community participation

The training also helped the LS to involve the wider community wherever and whenever needed. Community participation is one of the principles of CBR (Helander et al., 1989). The term "community participation" is commonly used in many community development programmes including CBR. The achievement of community participation is a long journey from contribution of a place to run a clinic or time or money to the community taking charge and owning the programme. In VCBR, it was thought that recognizing and responding to the needs of the non-disabled community by CBR would facilitate community participation in CBR. Attempts were taken to achieve community participation through the organization of health-screening camps for the whole community, health and disability awareness sessions, exhibitions, school awareness and the establishment of a referral system to cater to the general health needs of both PWD and non-disabled people. There were some indications that increased community awareness enhanced the supportive networks for PWD. The formation of 'Friends of PWD' is an example of one such supportive network.

2.3.7 Transfer of knowledge and skills within the community

The training programme for the LS was flexible enough to respond to the training needs identified by the LS through their interactions with PWD. Through the training the LS acted as agents for the transfer of knowledge and skills to the PWD and their families.

Transfer of knowledge and skills about disability and rehabilitation related issues also took place in the wider community. School awareness sessions and community awareness sessions are some of the examples. The purpose of this training (awareness) was to encourage wider community participation. During this training, non-disabled people were sensitized to the abilities, needs and problems of PWD. Building knowledge capital among PWD, their family members and the wider community was an attempt to achieve sustainability of CBR. In the VCBR training, the trainers respected the role of the LS as the primary care givers in the community. They encouraged the LS to take responsibility for the direct intervention for PWD and their families. Even when the trainers conducted practical training sessions, review and follow-up of PWD in the community it was always along with the LS. This led to improved confidence and empowerment of the LS, and greater acceptance of the LS in the community.

2.3.8 Logistics of Training

Two to three training sessions were held each week. The training used a problem-oriented approach, which enabled both the Educators and LS to device practical and innovative responses to each particular problem. This mutual education enriched the process of continuous learning and was challenging both for the LS and the Educators. Formative assessments before and after each training session were used to evaluate teaching, learning and learning needs. A total of 155 training sessions were conducted and on average each LS was able to attend 90% of the sessions.
(Appendix 3 for a brief outline of the VCBR Training Programme)

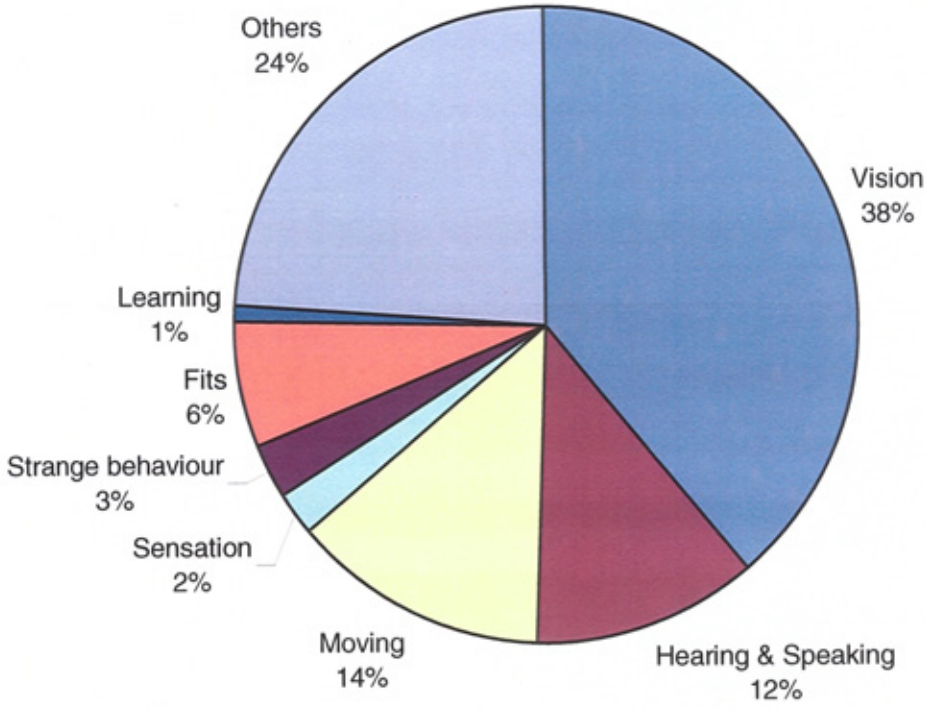
2.4 Identification of disability

The LS were trained to identify PWD and their felt needs. Each LS carried out initial house-to-house surveys in their communities each covering a population of 2,000 to 3,000 (Total population 23,272). They used the survey format in the WHO training manual and identified 2036 of the population (8.75%) living in the

VCBR coverage area as PWD (Figure 2.4). The WHO estimates that globally the prevalence of PWD in any community ranges from 7-10% of the population (Elwan, 1999).

In India, there are two major sources of information regarding the prevalence of disability. They are Census of India (Registrar General & Census Commissioner India, 2001) and sample surveys by the National Sample Survey Organization (National Sample Survey Organization - Government of India, December 2003). The prevalence of PWD in both these surveys was 2.3% and 1.8% respectively. The probable reasons for this low figure and the disparity with the VCBR survey results could be lack of understanding of the concept, varied classification of disability and less priority given to identifying disability when the survey was conducted as part of a larger census operation. Estimating the prevalence of disability accurately would help in planning health services at national, regional and local levels as well as policymaking. The prevalence of disability in VCBR coverage area is in accordance with prevalence suggested by the WHO. The training of the LS supplemented the pre-existing knowledge that the LS had by sensitizing them to the concepts of disability. The assurance that the identification would be followed by appropriate service delivery further strengthened the motivation of LS to identify the PWD and also encouraged families to disclose information on PWD in their homes. This is in contrast to other surveys where it is noted that PWD may be hidden and hence not reported (Sauvey S, Osrin D, Manandhar DS, Costello AM, & Wirz S, 2005). The CBR Network (CBR Network, 2002) has suggested that mere surveys without any follow-up services should be discouraged. Additionally since they belong to the community, the LS were able to involve others in the identification of PWD while they were completing the survey.

Figure 2.4 Distribution of primary disabilities within the community as identified by the LS through initial house to house survey (N=2036)



Whilst this survey has identified primary disabilities there is published evidence to suggest that between 38 to 49% of PWD have some degree of communication disability (Hartley & Wirz, 2002).

With time and experience, the LS developed their skills and with the use of innovative approaches they identified more PWD. During the survey the LS identified many people with multiple disabilities and also with some chronic medical conditions such as cancer, HIV. These people were categorized under 'others' category.

2.5 Intervention and Referrals

Following the prevalence survey, the needs of PWD were identified using a WHO proforma for the same. They identified 1325 (65%) who needed intervention according to project protocol. On further discussion however 964

PWD did not feel the need for any intervention. The needs of 361 PWD who asked for help from the project were found to be varied and related to different areas such as mobility, vision, vocational settlement, speech and hearing. The LS were able to address the needs of 207 PWD within the community itself. 154 PWD were referred either to the secondary or tertiary care centre by the LS.

Some problems were complex enough to warrant field visits by the VCBR staff including the medical team. During these visits, the team and PWD together analysed the situation and suggested interventions including referral to secondary and tertiary centres as appropriate. Sometimes the problem needed the help of the Government systems or of the local leaders. (e.g. Linking persons with DOTS scheme for Tuberculosis; facilitating PWD to get Identification card (ID card) from the District Disability Rehabilitation Office.

Those who needed to be followed up after intervention at secondary and tertiary care centres have been referred back to LS for further follow-up. Wherever possible the LS were involved during their admissions in the secondary care centre.

The location and type of intervention depended largely on the nature of disabling condition and severity of the disability. For example, a person with difficulty seeing due to cataract was referred to a tertiary care centre (eye hospital) for cataract surgery and fixing of IOL or prescribing spectacles. A person with fractured femur who had difficulty moving even after a series of bone settings done in a traditional bone-setting centre, was mobilized in the community with available resources.

On some occasions, the intervention was advice, support and regular follow-up. A person with fits who was advised to take regular medication by the hospital, was visited by the LS to ensure regular intake of medicines and monitoring the health status. The social needs of PWD were met by linking with existing government and non-government programmes.

Some interventions brought immediate results and some did not. A person with mild stroke showed improvement by regular exercise with the LS and the cooperation of the family members. In contrast, a child with mental retardation in spite of regular visits and intervention by the LS did not show significant improvement. Although the team could see some improvement, the family members were unable to perceive it. These 'dynamics of intervention' were taught to the LS as part of their training. VCBR followed a strategy of dealing with simple problems in the beginning, slowly expanding to cover more complicated problems with time and experience.

2.6 For the community as a whole

The environment also influences the quality of life of PWD. The attitudinal barriers and the architectural barriers influence the PWD directly. The community needs to be sensitized about the special needs of PWD through various strategies like organizing awareness programmes, exposing the abilities of PWD to the public and creating opportunity for the community members (non-disabled persons) to experience the disability by simulated activity.

General Health Screening Camps were conducted in response to repeated requests from community members (non-disabled people) about basic unmet health needs. During these camps, screening for common illnesses, diabetes, and hypertension were done. The VCBR used these camps for creating awareness about the prevention of disability and the special needs of PWD. LS were actively involved in organizing these camps, which helped in linking the LS with health and disability related issues in their community. Involvement in general medical care enhanced the image and prestige of the LS within their communities.

Exhibitions on general health issues for the public were used as a platform to educate the public regarding the problems and abilities of PWD. School children were a captive group with the potential for change that the VCBR

made use of. In VCBR, efforts were taken to organize awareness sessions in two schools located in the VCBR coverage area. One of the LS organized the school children in her area and awareness sessions were held for them. Through dramas, role-plays, competitions and skits children were made aware of the abilities of PWD, prevention and early identification of disability and their roles in the lives of PWD. Working with children had the added advantage of the message reaching a wider circle of teachers, parents and other children. In total, 42 awareness sessions for school children were conducted.

2.7 Evaluation

Evaluation in this project was a systematic way of learning from experience through critical analysis so that the successes were retained, replicated and the mistakes avoided in the future. Evaluation was of the process of implementing the programme and enabled critical review to be part of the planning itself.

Concurrent or ongoing evaluation took place on a day-to-day basis. Terminal evaluation was carried out at the end of the project or a phase of the project. Since evaluation called for objective and critical analysis, it was important to have adequate information to do this. Through pre and post tests, the knowledge and attitude of the LS during the training were assessed. The LS gave feedback on the content and methods of training and all this information was used to improve the training programme. The LS were assessed during field visits by the staff and ongoing training focused on areas identified for further training.

Through weekly review with VCBR staff, the processes of the programme were evaluated on a regular basis and programme plans modified or changed accordingly. (e.g. It was decided to make a bar chart of LS attendance for the training each month and use this as a motivating tool to achieve regularity)

Each special programme such as a health camp, eye camp or school awareness had a post evaluation and the feedback was utilized to improve the

next activity. (e.g. As part of health screening camp, it was decided to keep one or two wheelchairs and a hurdle for the public to experience the disabling condition in a wheelchair)

Both quantitative and qualitative information were collected in the VCBR. Through regular review meetings, the team including the LS critically looked at the information collected during the survey, needs assessments undertaken by the LS and progress made through intervention. In this way the regular evaluations made the LS central participants in their learning experience as well as providing rich evidence to the overall case study.

In any community *development* project, the long-term outcomes will be the true test of success. However, it is important that the community, including PWD develop skills and contributes to the evaluation. Campfens (Campfens D, 1998) identified process (ongoing) and impact (long-term) as two principal types of CBR evaluation. In VCBR, both quantitative and qualitative information was used for evaluation.

2.8 Summary of the Context: VCBR and the PhD study

The aim of VCBR was to improve the QOL of PWD. The salient features of this were:

- ✓ VCBR access 9 slum communities within the Vellore Town
- ✓ Local Supervisors (Volunteers) were trained to deliver community based rehabilitation services to PWD whom they identified
- ✓ Facilitated referral to secondary and tertiary care resources through the LS for PWD and the wider community

The study was undertaken within the context of this VCBR project. The aims of this study were to find out the impact of this particular model of CBR on the lives of PWD including the significance of the secondary and tertiary care services. Therefore it is important to have a good understanding of the context within which the VCBR was carried out.

CHAPTER 3 REVIEW OF LITERATURE

3.1 Introduction

Over the past twenty-five years, many of the basic concepts related to CBR have been subject to reflection and change. The concepts of disability, rehabilitation, the emphasis placed on human rights, action to address inequalities and alleviate poverty and the expanding role of Disabled People Organizations (DPO) have all been evolving over time (Helander E, 2007).

3.2 Evolving concepts of Disability

Disability affects physical nutritional and psychological health as well as the social relationship of people, life in the realms of family, friends, and neighbours and level of independence (Barbotte, Guillemin, & Chau, 2001; Pai M et al., 2001). The consequences of disability can have an impact at personal, interpersonal, family and social levels. Although disability is as old as the human race, the issue of disability and the experiences of disabled people had received little consideration in general academic circles till recently (Oliver, 1990). Since 1990, many universities in the UK are offering disability related courses and this has led to improvement both in academics and research in disability. However in many other parts of the world this is still not the case and these issues have been marginalized. Only in the disciplines of medicine and psychology, has disability been given an important place. People with disabilities remain at the margins of society as one of the impoverished groups (Imrie, 1997). The International Year of Disabled Persons in 1981 stimulated much interest worldwide in disability (Dalal, 2002). However the progress has been slow and varied in many developing countries. Apart from a few examples of individuals with disability who have been achievers, the majority of PWD still face discrimination and are marginalized. For example, Javed Abidi a PWD who is an activist and is a pioneer in implementing the disability rights act in

India said about his preventable disability, "I am not angry or bitter about what happened....I am one hundred times more privileged than the vast majority of disabled in this country-what is happening to hundreds of thousands of other people" (Bornstein, 2005, p.212). There are other PWD who have achieved in varied areas related to disability sector despite having disability are few in the majority of PWD for example Dr. Mary Verghese in the field of rehabilitation of persons with spinal cord injury (Wilson, 1963); Major. Ahluwalia who held the responsible position in the Rehabilitation Council of India and the founder of Indian Spinal Injury Society (Wikipedia, 2009); Mr. Ramakrishnan, the founder of Amar Seva Sangam, a NGO working for and with PWD in southern India (Reporter, 2007).

In 1980, the WHO published the first edition of the International Classification of Impairment, Disability and Handicap (WHO, 2001a). In this, disability was seen as a result of impairment and handicap was seen as a result of impairment or disability or both. The issues related to disability were limited to the individual person. Over a period of twenty-five years, this classification has been revised and field-tested. The concept of disability has widened from being centred around an individual to seeing individuals within their particular context. The International classification of functioning (ICF) has moved away from being a "consequences of disease" classification to become a "components of health" classification (WHO, 2002). Components of health identify the constituents of health whereas "consequences" focuses on the impacts of diseases. These changes have taken place within the medical and social models of disability (Llewellyn & Hogan, 2000).

3.2.1 Models of disability

In the field of rehabilitation, many models have evolved as professionals, PWD, their family members and the wider community work together to improve the QOL of PWD.

"The medical model views disability as a feature of the person, directly caused by disease, trauma, or other health condition, which requires medical care

provided in the form of individual treatment by professionals. Disability, in this model, calls for medical or other treatment or intervention, to 'correct' the problem with the individual" (WHO, 2002, p.8). Investigations will tend to concentrate on the individual and see the way forward as giving some form of treatment to the PWD. The overall picture is that the human being is flexible and 'alterable' while society is fixed and unalterable. The emphasis is upon adaptation to the environment. Courage, independence, will-power are all lauded especially in cases where a PWD overcomes problems associated with disability through individual effort (Johnston, 1994). The medical model is said to have three sub models namely individual, charity and administrative models (Chib M, 2002). The individual model may also be called as tragedy model which considers PWD as passive, inert and dysfunctioninig. In the charity model, PWD are made to feel grateful to the society because of help received from government and other philanthropists. The administrative model looks at PWD from various angles and provides comprehensive rehabilitation which tries to normalize the individual PWD as much as possible. Although the administrative model is primarily medical, it has some elements of a social model.

As a result of increasing emphasis upon the importance of social factors in the maintenance of disability, the inadequacies inherent in clinical models of disability have been thrown into focus.

Within a social model of disability it is argued that individuals who are different by virtue of an impairment find that they are oppressed by societal views of normality. In other words, disability only exists in so far as it is socially constructed and imposed on people with impairments (Hutchison, 1995). The social model of disability puts the problem back into the collective responsibility of society as a whole and there is a de-emphasis upon the individual. Social theorists see disability as emanating from society and emphasize that social circumstances can influence the level of disability observed. In contrast to the medical model, the social model emphasizes that individuals who are different by virtue of an impairment find they are oppressed by a society obsessed with concepts of normality. Oliver (1995) has put forward a social definition of

disability 'the disadvantage or restriction of activity caused by a contemporary social organization which takes no account of people who have physical impairments and learning difficulties and thus excludes them from mainstream social activities'. This definition permits psychological wellbeing to be comprehended in a manner that emphasizes the dynamic relationship between an individual's impairment and environmental disablement. Practitioners within the clinical professions have viewed the social model as a denial of what is an objective truth about ability, and claim that the social model does not adequately address how we can identify individual truth, perceptions and belief about disability (Hutchison, 1995).

The medical model of disability was criticized and a social model was suggested by the disabled people. The 'professional' language used in the medical model is an example of one the issues raised by PWD. Words such as 'patients' were changed to 'clients' then 'consumers' then 'customers' declaring that the medical aspects of disability are not the only defining features of a person (Vash, Summer 2004). Subsequently, the medical and social models have been critically studied by rehabilitation experts and DPOs. New models have been proposed and the existing ones supported or criticized. It is clear that looking at disability only through a narrow lens of one particular model may not always solve the problems of PWD (Dewsbury, Clarke, Randall, Rouncefield, & Sommerville, March 2004).

A model called the 'Affirmation Model', which was advocated by disabled people through the Disability Arts Movement directly opposes the view of impairment and disability taken by the medical model. In fact they refer to the medical model as the 'tragedy model'. The affirmation model builds on the social model through which disability is redefined. The affirmation model of disability affirms that disabled people whether impaired or disabled have a positive identity in society. This positive identity rejects the value of normality that currently exists in society and encourages celebration of difference. Many disabled people state in their writings that being disabled has many advantages/benefits (Swain & French, 2000). For example, their basic needs are met by the government through social security benefits. While this may be

true in countries where there are government social security schemes in operation like the UK and Australia it may not be applicable in countries where PWD live a hand to mouth existence. The perception of disability is also associated with dominant cultural norms with regard to abilities and appearance. The normalisation-based typology (Darling RB, Dec 2003) will be inappropriate if everyone in the society feels proud of their disability. A Malaysian disabled woman, who underwent studies in special schools proudly stated that she has received a high standard education compared to her siblings because of her disability. However this may not be the case where the priority in sharing of household resources is for non-disabled children rather than disabled children, and government schemes/benefits are not widely available. In India particularly in the Hindu religion, disability is sometimes perceived to be the result of sin and destiny called as karma (Dalal, 2002). Lang (2001, p.9) in a group interview with PWD in a CBR programme at South India reported that, "People are afraid to come in contact with disabled people. They think that disability is contagious. Some people in the community tell others to avoid disabled people because they might also attract the bad luck of the disabled person and the family."

Although the social model of disability was finding its place in the disability sector especially in the field of disability research some activists did not like the way this model has been recognized. Tom Shakspeare is among those who strongly criticized the overwhelming emphasis given to the social model and stagnation in the area of disability research due to this. He described the inadequacy of social model in terms of connecting the disabling condition with the social context alone and he came up with an alternative disability approach called interactional or relational approach (Shakespeare, 2006). Models of disability seem to reflect the type of research methodologies in the disability field. It would seem that, participatory research, which encourages power sharing between the researcher and the researched reflects the concerns and views of disabled research participants and thus tends to reflect a social model of disability. However, participatory methodology is not inherently associated with a social model of disability (Swain & French,

2004). The existence of different models of disability has a direct relationship on how disability research, rehabilitation strategies and educational materials are organized. Models of disability have also prompted development of tests for assessing functional aspects and quality of life of PWD. For an example, the disability model of the National Centre for Medical Rehabilitation Research, which is a reformatted version of ICF promoted by the WHO was used to develop a tool for assessing the functional status of infants called 'the Test of Infant Motor Performance'(Campbell, June 2006). In rehabilitation, the strategy depends on which type of model of disability the stakeholders follow to suit the needs of PWD.

The various models proposed to explain and classify disability may be expressed in a dialectic of "medical model" versus "social model". The *medical model* views disablility as a "personal" problem, directly caused by disease, trauma or health conditions, which requires medical care provided in the form of individual treatment by professionals. Management of disablility is aimed at the person's better adjustment and behaviour change. Health care is viewed as the main issue and at the political level it is health care policy that needs to be modified. The *social model* of disability, on the other hand, sees the issue mainly as a "societal" problem from the viewpoint of integration of persons with disabilities into society. Disability is not an attribute of a person, but a complex collection of conditions many of which are created by the social environment. Hence the management of the problem requires social action and it is the collective responsibility of society to make the environmental modifications necessary for the full participation of people with disabilities into all areas of social life. The issue is, therefore, an attitudinal or ideological one which requires social change, while at political level it is a question of human rights. Hence the issue is highly political for all intents and purposes.

A PWD is not an individual in isolation but is located within a particular context in which they belong. The context should not be ignored in deciding whether to reject or promote a particular model or to develop a new model. Disability is always an interaction between the features of the person and features of the

overall context in which the person lives. The International Classification of Functitioning, Disability and Health known more commonly as ICF has brought a composite model called "biopsychosocial model", which is basically an integration of medical and social models (WHO, 2002). In ICF, disability and functioning are viewed as outcomes of interactions between health conditions (diseases, disorders and injuries) and contextual factors. There are external environmental factors (attitudinal and architectural barriers, government policies and law) and internal personal factors (gender, age, coping styles, socio-vocational aspects, behaviour pattern and character) which influence how disability is experienced and perceived by the individual.

In summary, various models of disability exist which are broadly based on the professional's perspective (medical), the individual's perspective of his/her own disability and also on the sociological perspective, which includes social norms, social movement by activists and government policies regarding welfare and legal aspects of PWD. Instead of uselessly arguing about models of disability, it would be better to encourage whichever model or combination of models that facilitate the growth of rehabilitation, enhancing the QOL of PWD (Llewellyn & Hogan, 2000).

Hartley and Wirz (2005) observed that a lot of time and energy has been spent in clarifying terms and the concepts of disability. Although this has resulted in growth in the field of disability they strongly oppose the manner in which the debate on the various models or approaches to disability are currently carried out. They advise that it is time to stop arguing which model is best and start to work towards a comprehensive approach that respects and includes all that is best in the field of rehabilitation today.

3.2.3 What is disability?

Defining disability is complex and controversial. Acceptable terminology changes over time and it is important to consider the perspective of disabled people. Two key terms, 'impairment' and 'disability', are often used synonymously. However, they are different, and it is important to make the

distinction. Impairment (physical or intellectual) has been defined as lacking all or part of a limb or having a defective limb, organ or mechanism of the body. In contrast, disability has a social and human rights dimension, since the person with an impairment is excluded by the actions of others. Disability is the disadvantage or restriction of activity caused by contemporary social organisation which takes little or no account of people who have impairments and thus excludes them from the mainstream of social activities (Oliver, 1995). Some campaigners question the use of 'impairment', which is in common usage in disability literature, due to its negative emphasis (Llewellyn & Hogan, 2000). The term 'condition' is more neutral: a condition may or may not be perceived as an impairment, it may or may not restrict function, it may or may not be life-threatening (for example, high blood pressure, epilepsy, lack of a limb, etc). However, while many people may have a debilitating health condition or a permanent condition such as short sight, they are generally not disadvantaged in the same way as disabled people are as result of their impairments (Enfield, 2001).

According to the International classification of impairment, disability and health, 'disability is an umbrella term for impairments, activity limitations and participation restrictions'. It denotes the negative aspects of the interaction between an individual (with a health condition) and that individual's contextual factors (environmental and personal factors). 'Activity limitation' replaces the term "disability" and "participation restriction" replaces the term "handicap" used in the 1980 version of ICIDH (WHO, 2001a).

3.2.4 Quantifying Disability

There are relatively few censuses, surveys, and registration sources of information on disability in developing countries, and conceptual and definitional problems abound. However, several attempts have been made to find out roughly how many people in the world are disabled, what the main causes of disability are, and how the disabilities encountered in different countries and regions affect quality of life. The World Health Organization noted, in 1981, that it was impossible to estimate the number of disabled

people more accurately than at 10% of the total population, and the WHO range of 7-10 percent has often been cited (Elwan, 1999). UNDP estimates that globally, one in 20 people has an impairment (physical or learning) and that over 75% of people with impairments live in a developing country (Helander, 1992). Other sources suggest that this is a conservative estimate, with as many as one in ten people having a disability. In many countries, the high mortality rate among young people with disabilities reduces the recorded incidence of impairment. If disabled people who have died are included, disabled people may be a substantial minority within the population (Albert, McBride, & Seddon, 2004). And the population of disabled people is growing. Medical advances mean that people with profound and multiple impairments have a greater chance of survival, while industrial and traffic accidents increase the number of disabled people. In addition, a higher overall life expectancy of a population means that impairments caused by the normal processes of ageing become more prevalent. A study carried out in Botswana CBR programme suggested that more CBR programmes to be established to cover the increasing ageing population and their increasing of health needs (Nordholm & Lundgren-Lindquist, 1999).

In 2006, the statistics division of United Nations (DISTAT) initiated a collection of statistics on disability by referring census, survey and administrative records from 76 countries. According to DISTAT, prevalence rates should not be compared across countries due to differences in the concepts and methods used to identify persons with disabilities (UN-DISTAT, 2006). In addition, fundamental differences in disability definitions also impact on prevalence estimates across countries. Developed countries typically use disability screens that assess activity limitations (e.g., limited ability to work), whereas developing countries tend to use impairment screens (e.g., inability to hear, see). Finally, the wording and sequence of questions also compromise the comparability of prevalence estimates across countries (Mitra, May 2005). It is also observed that in general, surveys tend to report higher rates of disability than censuses. This could be because of type of questions asked on censuses compared to the more detailed and various questions posed on surveys. (ref Table below (Mont, March 2007)

Prevalence of disability in selected countries by source

Census			Surveys		
Country	Year	Percent of population with a disability	Country	Year	Percent of population with a disability
United States	2000	19.4	New Zealand	1996	20.0
Canada	2001	18.5	Australia	2000	20.0
Brazil	2000	14.5	Uruguay	1992	16.0
United Kingdom	1991	12.2	Spain	1986	15.0
Poland	1988	10.0	Austria	1986	14.4
Ethiopia	1984	3.8	Zambia	2006	13.1
Uganda	2001	3.5	Sweden	1988	12.1
Mali	1987	2.7	Ecuador	2005	12.1
Mexico	2000	2.3	Netherlands	1986	11.6
Botswana	1991	2.2	Nicaragua	2003	10.3
Chile	1992	2.2	Germany	1992	8.4
India	2001	2.1	China	1987	5.0
Colombia	1993	1.8	Italy	1994	5.0
Bangladesh	1982	0.8	Egypt	1996	4.4
Kenya	1987	0.7			

Source: United Nations Statistics Division; IBGR (Brazil), INEC (Nicaragua), INEC (Ecuador), INEGI (Mexico), Statistics New Zealand, INE (Spain), Census of India 2001, SINTEF Health Research (Zambia) 2006

3.3 Evolving concepts of Rehabilitation

According to Wade (2003, p.876), rehabilitation is defined as "a reiterative problem solving and educational process that focuses on disability (altered activities) and aims to maximize participation in society while minimizing the stress on and distress of the patient and family". Most of the rehabilitation services in India follow the biomedical model in which hospitals and primary health centres play a key role. Disability is viewed as a disease state and the emphasis is to cure, correct or ameliorate the problem so that persons with disability become as "normal" as possible. The focus is on disability, which is perceived as a problem for a particular individual to be handled by competent medical experts. The attempt to make some of these services widely available in the community led to the development of the welfare model of rehabilitation.

Funding agencies, including international agencies like WHO and UNICEF found this welfare model a good one to support. In this model, people are treated as 'passive recipients' of welfare services, which primarily concentrates on free distribution of medical aids and appliances to the poor and needy among the disabled These practices only reinforced the culture of dependency (Dalal, 2002). Given the magnitude of the problem, limited resources and poor infrastructure, these schemes hardly had any impact, reaching out to only 2-3% of the needy population (Dalal, 2002). Even among them, the researcher feels that most of the aids distributed are not used or inappropriately used because of poor training and follow-up.

In the 1980's in India, there was an ideological shift from welfare to human resource development. The idea was that, rather than making people passive recipients of state welfare, people should be viewed as a human resource, which should be fully developed through education and training. There was a dawning realization that neither charity, nor welfare, nor a human resource development model alone, could succeed in a country like India. The view that rehabilitation services need to be community based and integrated across different disciplines was gaining support from all quarters (Dalal, 2002).

The enactment of the Persons with Disabilities Act, 1995, by the Indian government ensures equal opportunities, protection of rights and full participation of people with disabilities in all spheres of national life. India was the first signatory to give effect to the proclamation on the full participation and equality of the PWD in the Asian and Pacific Region (GOI, 1996). By enacting this law, the government has demonstrated that in addition to the welfare of the PWD, the rights of the PWD are also significant.

The Joint Position paper by ILO, UNESCO & WHO (2004) emphasizes that rehabilitation services should no longer be imposed without the consent and participation of people who are using the services. Rehabilitation is now viewed as a process in which PWD or their advocates make decisions about what services they need to improve the quality of their lives. Professionals who provide rehabilitation services have the responsibility to provide relevant

information to PWD so that they can make informed decisions regarding what is appropriate for them.

David Werner, the founder of a well-known CBR programme in Mexico, emphasizes that disabled persons are the leaders in the problem solving process. The collective problem solving process by PWD, community rehabilitation workers and specialists is the strength of their programme (Werner, 1998b). Johnson (2001) suggested the following trends and changes have occurred in the disability sector since the International year of disabled persons in 1981 (Fig 3.1).

Figure 3.1 Trends and changes in the disability area (Johnson, 2001)

Medical orientation	→	Social Orientation
Narrow definition	→	Wide definition
Negative attitudes	→	Positive attitudes
Disability / Weakness	→	Ability / Strength
Segregation	→	Integration
Exclusion	→	Inclusion
Dependency	→	Empowerment
Institution based rehab	→	Community based rehab

There are many individuals/organizations/DPOs involved in sustaining these trends. Though many of these trends and changes are positive, some of the components like medical orientation and IBR are relevant in the process of rehabilitation.

3.4 Community Based Rehabilitation

The 1969 meeting in Dublin of the International Society of Rehabilitation (now Rehabilitation International) voiced some of the first public misgivings concerning the institution-based model of rehabilitation (O'Toole & John, 1991). The experts noted the significant disparity, which existed between needed

services and available provision, and acknowledged that the gap could not be closed by developing conventional services. It was recognized that the pace at which personnel were being trained was not adequate to meet the existing problem. There was a realization of a need to identify new forms and patterns of services, which required fewer professionals, less advanced forms of training, simplified methods of rehabilitation, and which could facilitate an expansion of the existing rehabilitation provision. Questions were asked concerning methods of providing the most essential assistance to large numbers of persons, through the use of readily available resources.

The need for an innovative delivery system was recognized and the World Health Organization (WHO, 1977) recommended the provision of essential services and training for disabled persons through community-based rehabilitation (CBR) as part of the 'Health For All' campaign. The emergence of the concept of primary health care entailed the acceptance of two important principles, which had been vigorously resisted earlier. Firstly, that it is more important to bring about even small improvements among the entire population than to provide the highest standard of care for a privileged few. And secondly, that non-professionals, with limited training, could provide crucial services.

The World Health Organization has provided the stimulus for incorporating rehabilitation into primary health care with the publication of a manual, Training the Disabled in the Community (Helander et al., 1989). The World Health Organization initiated the first version of the manual in 1979. Its dissemination and use in about 60 countries in the first ten years has facilitated the promotion of this concept (O'Toole & John, 1991).

3.4.1 What is CBR?

The most accepted working definition of CBR is by the WHO, ILO and UNESCO (2004, p.2). According to them, "CBR is a strategy within general community development for the rehabilitation, equalization of opportunities and social inclusion of all people with disabilities. CBR is implemented through the combined efforts of PWD themselves, their families, organization of

communities, and the relevant governmental and non-governmental health, education, vocational, social and other services". While this is a goal to be attained, many communities are still on their way towards achieving this type of CBR.

3.4.2 Principles of CBR

The five basic principles of CBR strategy as listed by Helander include

1. Active participation of disabled persons, their families and communities in all aspects of CBR with utilization of available resources in the community.
2. Transfer of knowledge about disabilities and skills in rehabilitation, to people with disabilities, families and communities.
3. Community involvement in planning, decision-making, and evaluation.
4. Utilization and strengthening of referral services that are able to perform skilled assessments with increasing sophistication, at district, provincial, and national levels, make rehabilitation plans, and participate in training and supervision
5. Utilization of a co-ordinated, multisectoral approach (Helander, 1992).

The WHO and ILEP joined together and listed following principles of CBR which are overlapping, complementary and inter-dependent.

1. Inclusion – placing disability issues and PWD in the mainstream of activities
2. Participation – encourage active participation of PWD, their family members and the local community
3. Empowerment – PWD and their family members are encouraged to make decisions and control the resources by way of leadership roles.
4. Equity – emphasizes equality of opportunities and rights
5. Raising awareness – addresses attitudes and behaviour within the community and also promotes inclusion of disability in all developmental initiatives.

6. Self-advocacy – CBR consistently involves PWD in all issues related to their well-being by way of mobilizing, organizing, representing and creating space for interactions and demands.
7. Facilitation – CBR requires multisectoral collaboration to support the community and to address the individual needs of PWD.
8. Gender sensitivity and special needs – CBR is responsive to individuals and groups within the community with special needs.
9. Partnerships – CBR depends on effective partnerships with community based organizations, governmental organizations and other organized groups.
10. Sustainablility – CBR activities must be sustainable beyond the immediate life of the programme itself. (WHO, 2007)

It is interesting the see the growth of wisdom of key principles of CBR from 1992 to 2007.

In performing all the above activities in the WHO model, the CBR worker is the lynchpin at the community level, and this is a role often played by community volunteers. It is the community CBR worker who provides information to disabled people and their families, e.g. advice about basic functional rehabilitation activities, construction of simple assistive devices to improve independence in daily activities, use of sign language, or use of a walking cane by a person who is blind (ILO, UNESCO, & WHO, 2002). The community CBR worker also acts as an advocate for people with disabilities, by making contacts with schools, training centres, work places and organizations, to promote accessibility and inclusion of community members with disabilities (ILO et al., 2002).

3.4.3 CBR and Adult learning

The community CBR worker may be a volunteer or a paid worker. Usually they are selected from the community where the CBR is in operation. Transfer of knowledge and skills to PWD and their families, which is one of the principles of CBR is mostly done through them. They are trained in the CBR programme itself by the programme managers. Their training is based on the adult learning

theory called Andragogy. Reischmann (2000, p.1) says, "Andragogy comprises the 'lifewide learning' of adults. This includes not only the institutionalized forms of learning, but also self-directed and even partly-intentional or non-intentional forms of learning." Malcom Knowles was the person who introduced the concept of andragogy to the English speaking adult education world. Knowle's concept of Andragogy – "the art and science of helping adults learn" is built upon two central, defining attributes: first, a conception of learners as self-directed and autonomous; and second, a conception of the role of the teacher as facilitator of learning rather than presenter of content emphasizing learner choice more than expert control" (Pratt, 1998, p.12).

3.4.4 CBR and Social Capital

Community participation and community involvement including the PWD and their families are important components of any CBR programme. A PWD is not an individual in isolation but is part of the many networks that exists within any community. These networks along with norms, relationships, values and informal sanctions that exist in any community form the 'social capital' for that community (Aldridge, Halpern, & Fitzpatrick, April 2002). These elements would vary depending on the local context. Awareness and identification of these elements of social capital in each local context is important for any CBR programme. Additionally, a good understanding and effective use of such 'social capital' would enhance the QOL of PWD.

3.4.5 Strengths and Weaknesses of CBR

David Werner has presented some of the strengths and weaknesses of CBR in his book "Nothing About Us Without Us" (Werner, 1998a, p.10) which are given below:

Figure 3.2 showing the major strengths of CBR

MAJOR STRENGTHS
Rehab for all – Tries to reach all disabled persons, with most concern for the poor
Comprehensive plan with social focus
Community education and involvement.

Figure 3.3 showing the major weaknesses of CBR

MAJOR WEAKNESSES
Usually organized for, not by, disabled people
Structure often Top-Down
Tends to follow pre-determined recipes, rather than to seek liberating solutions

The major strengths of CBR should be kept in mind and some of the weaknesses could be addressed over the period of time if the implementers are sensitive about them.

3.5 CBR in practice

In developed countries, community based rehabilitation is expanding, for example in the UK (J R Coll Physicians London, Sep-Oct 1997), Australia (Kendall, Buys, & Larner, 2000; McMullen & Mitchell, 1999) and the USA (Pace et al., 1999; Sandstrom, Hoppe, & Smutko, 1996) and also being found to be cost effective, for example in Poland (Bialkowska & Januszko, 1999). However the nature of the services provided is quite different to those provided in developing countries. CBR has also been used to provide services to people with amputations, spinal cord and head injuries, and in a war-torn environment (Lagerkvist, 1998). WHO, UNDP (Helander et al., 1989) have found that the need for rehabilitation services is most effectively met in developing countries through a Community Based Rehabilitation programme. As a result, there has

been a growing amount of literature exploring this (Mitchell, 1999). Since 1980, CBR has been implemented in developing countries such as the China (Ran, Wen, Yonghe, & Honglu, 1992; Zhuo & Kun, 1999), Eritrea (Grut L et al., 2004), Pakistan (Finnstam, Grimby, Nelson, & Rashid, 1988), Palestine (Arne H. Eide et al., 2005), Philippines (Lopez JM et al., 2000; Valdez & Mitchell, 1999), South Africa (Chappell & Johannsmeier, October 2007), South Korea (Kim & Jo, 1999),Uganda (Claussen J et al., 2005), Zimbabwe (H. J. M. Finkenflugel et al., 1996; Mpofu, 2001) and Vietnam (Hai & Chuong, 1999) including urban projects (Finnstam et al., 1988; Zhuo & Kun, 1999).

In some countries, the government implements CBR while in others, NGOs have taken the initiative. In India, the government has recognized the importance of CBR outcomes and hence suggested the need for CBR in its latest national policy on PWD (GOI, 2006). But in the experience of the researcher, most of the CBR programmes are run by NGOs in India.

Community Based Rehabilitation covers a wide range of activities related to disability. Many projects have found that their impact is maximized when they work collaboratively with different departments and agencies (Boyce & Johnston, 1998; Boyce et al., 1997).

The range of rehabilitation services provided should also be broad and extend beyond those found in traditional institution-based services, which tend to provide medical rehabilitation (Suelz, 1999) e.g. artificial limbs and mobility aids. Other approaches suggested are assistance such as education, vocational training and income generation (Suelz, 1999). The relationship of rehabilitation services to the culture in which they are developed has been stressed (Bischoff, Thorburn, & Reitmaier, 1996; Crishna, 1999). Also the need to nurture positive attitudes to people with disabilities during the training of CBR workers has been explored (Paterson, Boyce, & Jamieson, 1999).

Institutions, which provide outreach services through a team of professionals by visiting the community, may claim that they are doing CBR. Thus community

located / community outreach rehabilitation is confused with CBR. Sometimes these services can be developed into CBR.

Thomas and Thomas (1999) have found the term CBR used in different situations to describe a variety of activities as given below:

- ✓ Home-based services provided by families to disabled members of the family at home.
- ✓ Self help projects run by disabled persons.
- ✓ Out-reach projects run by rehabilitation institutions.
- ✓ NGO projects run by paid CBR workers.
- ✓ An ideology, which promotes inclusion of disabled persons in developmental projects.
- ✓ Institutional programmes located in the villages.
- ✓ A current fad to describe anything related to rehabilitation of the disabled persons.

The above list illustrates the scope and flexibility of the use of the term CBR. There are two ways of looking at this. One might comment on or criticize each of these as to whether it is true CBR or not. The other way is to look for positive factors, which adhere to the general principles of CBR. As long as the PWD are helped in the programme without robbing their rights under any label, it may not be useful to focus on the negative factors.

3.5.1 Initiation of CBR

Ideally CBR programmes should be need-based. In the experience of the researcher, the type of services delivered by CBR programmes depends largely on who initiates CBR and what resources they happen to have.

There are several successful CBR programme in various parts of the world initiated by different stakeholders. The stakeholders may be DPOs, associations of single disability or cross disability, rehabilitation experts, community development experts, INGOs (Kim & Jo, 1999), Governmental organizations (Souphan Inthirat & Thonglith, 1999; Zhuo & Kun, 1999), etc. Each has its own strengths and weaknesses. For example, the CBR by DPOs

has the advantage of raising the voice of the PWD for rights, equality and participation. But lack of expert support may mean that the medical and technical aspects of CBR are neglected.

CBR can be initiated depending on the ground reality. Ideally, the community expresses the felt needs of PWD and the need for CBR. Alternatively, the DPO themselves express the need for a CBR. But in practice, these ideal situations do not always exist. Lack of knowledge, awareness, resources and poor socio-economic conditions in communities dictate a less than ideal response. Considering the real situations in South Asia, Thomas and Thomas (2002a) suggest that CBR can be initiated by an external agency, who would encourage and motivate the community to shoulder the responsibilities in the course of time. In contrast, Barnes (2001) suggests that health planners should stimulate the formation of a group of PWD, before designing a service.

Formation of groups is not an easy or quick process, as it requires excellent understanding, motivation and trust among the members and confidence in the external agency. The external agency has to build good rapport with the community, and for this some services may need to be offered; but this should not delay the start of a CBR programme. This approach can be seen in many primary health care programmes in India, where health was the entry point into the community. This was followed by social and other development services including formation of youth clubs, women's associations, farmers' clubs, etc.

Werner has also mentioned that some CBR programmes expand their coverage to include a wider range of disabilities and related activities than they started with (NCSS, 1998). For example, in Mexico, physically disabled village health workers started a community programme for disabled children and their families called 'Project Projimo' and are now serving persons in all age groups with different disabilities. In Peshawar in Pakistan, a community programme for retarded children was started, and in Nicaragua, a group of persons with spinal injury started a workshop to make wheelchairs. Currently, both these programmes have expanded their clientele and activities.

3.5.2 Coverage

It is encouraging to note that the problems of a majority of PWD can be addressed in the community itself, provided there is a CBR programme in operation. WHO reports that 70% of the problems of PWD could be addressed in the community, while the remaining 30% would require rehabilitation services that are available in secondary and tertiary care centres because of the severity and complexity of the disability (Souphan Inthirat & Thonglith, 1999; WHO, 1981).

3.5.3 Referral System

Thomas & Thomas (2002b) suggested that a referral service is needed as part of CBR, exclusively for addressing the medical needs of women with disability. The IDDC recommended referral to district and national level services in some cases as well as for training and support (IDDC, October 2002).

A referral service is an integral part of any CBR programme so that the needs of people with complex or severe disabilities could be addressed in either secondary or tertiary care centres. Once intervention in secondary and tertiary care centres is completed, follow-up could be carried out within the community. Because secondary and tertiary care services are not widely available, many CBR programmes are unable to set up a good referral system. If the CBR programme is initiated by a specialist centre, it is possible to set up a good referral system as part of the CBR programme. This would ensure appropriate services for all PWD. If the CBR is initiated by PWD or parents of PWD, making links with appropriate specialist centres should be part of the project from its inception. However Helander (1992), suggest that these linkages could be made once the community needs are known and preferably after a certain period of implementation.

But in practice, this might delay the intervention for those with severe and multiple disabilities. When a CBR programme cannot link with a referral service, there is a possibility of creating discrimination among the disabled

persons by not providing services to people with severe and multiple disabilities.

3.6 Research in CBR

Research activity in CBR has been limited and fragmented. A number of authors have lamented this fact and suggested key topics to which the research energies in CBR might be channelled (Wirz, 1996).

Barnes (2001) has suggested that publishing the results of audit of CBR projects could be a way to overcome the paucity of research literature in this field. He has emphasized the need for CBR projects to undergo regular audit and for the results to be published.

Research in CBR would enhance growth and development in the field of CBR. There is an increasing emphasis today on evidence-based practices in the field of CBR. Different areas in the field of CBR are suggested as possible research priorities for academics and rehabilitation professionals. For example, the following four areas are suggested by Mitchell (1999):

- ✓ Service delivery system
- ✓ Technology transfer
- ✓ Community involvement
- ✓ Organization and management

Wirz (1996) has suggested the following areas for research

- ✓ Policy
- ✓ Organizational issues
- ✓ Role of women
- ✓ Efficacy of CBR interventions
- ✓ Role of CBR workers
- ✓ Give the idea that research can be generated in the community to answer common questions.

Although the research in CBR has been steadily growing especially in the area of service delivery there are other areas such as policy, efficacy of interventions still need to develop further. More research in the area of evaluation of variety of CBR programmes would facilitate the production of evidence-based practices. The WHO emphasizes, evidence based practices in the field of CBR (WHO, 2003). Considering the current situation of limited availability of published materials in CBR, an innovative method of looking at the grey literature for synthesizing evaluation reports to produce evidence has been recently undertaken (Pim Kuipers, Wirz, & Hartley, 2008).

3.6.1 Methodology in CBR research

Both quantitative and qualitative methodologies have significant value in the field of CBR research (Evans et al., 2001). O'Toole (1988) suggests that the effectiveness of CBR cannot be evaluated solely in terms of PWD's progress on a standardized test or a developmental checklist. Quantitaive gains need to be balanced with a qualitative analysis of the process involved.

In many evaluations of CBR programmes, the PWD are only evaluators, and are less often involved in the planning of the evaluation or indeed of the research programme. It is now increasingly recognized that PWD must be part of and involved in research activities from the planning stages. This is called emancipatory or participatory research. In many developed countries where there are strong networks and DPOs, this type of research could and does occur.

Wirz (1996, p.2) also supports participatory research (Swain & French, 2004), and according to her, "It is important to involve disabled people in the planning stage of research, whether that be research into disability issues in the north or CBR in the south". In Britain, research in CBR has its roots firmly planted in the British disabled people's movement and the writings of disabled people and their own organizations rather than the work of professional "scholars" working in academic institutions (C. Barnes, 2001)

In some countries, DPOs do not exist; in some they are newly formed and young organizations. Most DPOs seem to start out with single disability focus e.g. Associations for the blind or deaf. In most places there are no cross disability organizations where common problems of disabled people can be jointly addressed. In developing countries, the socio-economic status of PWD is much poorer compared with PWD in developed countries. Both government and NGOs involved in disability welfare programmes often work with limited resources. Their focus is on service delivery. Recently, it has been observed that there is a move from a service based to a rights-based approach (Bury, 2003).

Most research in CBR in developing countries is in the area of monitoring and evaluation. In most developing countries, considering the poor socio-economic and educational background, it is unrealistic to expect that PWD will plan and undertake research at this moment. Then who will do so? Can academics or professionals do the research? Robson (2002) has highlighted the importance of the practitioner-researcher. According to him, 'A practitioner researcher is someone who holds down a job in some particular area and is, at the same time, involved in carrying out systematic enquiry which is of relevance to the job.'

There are both advantages and disadvantages to being a practitioner-researcher when compared with an outside-researcher. It is recognised that experienced practitioners can understand the complex issues of CBR better than outsiders. This should be seen as a step in the process of evolving research in CBR. With time the hope is that PWD will be fully involved in CBR research from the beginning.

A few studies have been conducted to find the impact of CBR programmes on the lives of PWD. In a qualitative study done in three countries (Ghana, Guyana and Nepal) by the WHO and the Swedish Organizations of Disabled Persons International Aid Association, it was reported that the following CBR initiatives were perceived most useful by the PWD (WHO & SHIA, 2002).

- ✓ Social counselling
- ✓ Training in mobility and activities of daily living
- ✓ Providing or facilitating access to loans
- ✓ Community awareness raising
- ✓ Providing or facilitating vocational training / apprenticeship
- ✓ Facilitating formation of self help groups, parents' groups and DPOs
- ✓ Facilitating contact with different authorities
- ✓ Facilitating school environment

This is a special evaluation study giving voice to the PWD who have been in close connection with the CBR programme. At the same time it has a limitation of being done by an external person (foreigner) who is not familiar with local language thus there are possibilities of biased information.

Sharma (2007) carried out a review of the extent to which community based rehabilitation has been evaluated over the past thirty years using a Strengths, Weaknesses, Opportunities and Threats (SWOT) analysis. He has reviewed 22 publications that described or evaluated one or more dimensions of CBR. He found that the

Strengths were:

- ✓ a variety of methods used,
- ✓ most evaluations conducted in community settings,
- ✓ focus on mobility related evaluations by most programmes, and
- ✓ development of new instruments

Weaknesses were:

- ✓ lack of consistency in outcome measures,
- ✓ lack of cost-benefit and cost effectiveness studies,
- ✓ small sample size of many studies, and
- ✓ lack of focus on other than mobility related disabilities by most projects were some of the weaknesses.

Opportunities were:

- ✓ training assessments,
- ✓ use of mixed models,
- ✓ using indicators from a standard taxonomy, and

- ✓ focusing on medical rehabilitation.

Threats were:

- ✓ need to prioritize from diverse activities and
- ✓ having limited resources for evaluation.

This study has a special feature of looking at evaluation of CBR programmes, which are published in indexed journals. Although the SWOT analysis of various evaluation reports was done in a systematic way, it would have been better if these evaluation reports are categorized into socio-economic nature of various countries like developed and developing countries as the contextual factors will determine the nature of CBR. The living conditions of PWD, resources available to them, their expectations, culture and government policies and programmes are some of the contextual factors, which will influence the nature of any CBR programmes.

CBR is currently being adopted rapidly by both developed and developing countries (Lightfoot, 2004). However In literature, almost half of the publications in the area of 'community based rehabilitation' refer to 'out of hospital boundary' services that are located in the community. They are usually the community rehabilitation services provided in developed countries such as follow-up, home visiting, respite and day care services (Degeneffe et al., Spring 2008). The rationale behind organizing CBR in developing countries differs from that in developed countries. In developed countries, rehabilitation professionals are the key players in addressing the problems of PWD in the community. There is an extended rehabilitation services for people with specific disabling conditions like TBI, stroke, mental illness etc (Barbato et al., 2007; Degeneffe et al., Spring 2008; Powell et al., 2002; Stilwell, Stilwell, Hawley, & Davies, 1998; Wolfe & Tilling, 2000). These programmes aim at reducing the cost of hospital care. There are a few initiatives which depend on volunteers from the community (Pim Kuipers, Kendall, & Hancock, 2001; P Kuipers, Kendall, & Hancock, 2003). In developing countries, trained community rehabilitation workers/volunteers are the key players in addressing the problems of people with varied disabling conditions with the aim to improve the access to rehabilitation for the majority of PWD. Here too there are some initiatives which

focus on specific disabling conditions like mental illness, people with blindness etc (Chatterjee, Patel, Chatterjee, & Weiss, 2003).

Despite these differences in approaches there are still some principles, which are common to all of them. Taking the context seriously in planning and executing rehabilitation programmes is one such principle.

A review of CBR evaluations done by Mannan and Turbull (2007) suggested that future CBR evaluations should provide empirical evidence on whether or not it enhances quality of life of PWD.

3.7 Quality of Life (QOL)

Quality of life became an important priority in Western society following World War II. During the 1960's and 1970's in the United States, surveys to describe QOL were conducted. Research on QOL has been conducted in various fields like psychology, medicine, sociology, and epidemiology (Verdugo, Schalock, Keith, & Stancliffe, 2005). Though this term has been widely used in many fields there is no consensus on what exactly is meant by it.

Every person's life is different and thus the way in which each person experiences a quality of life is unique. Attempts have been made in various fields to define and clarify the concept of QOL by considering the complexity of an individual's life that is multidimensional. These attempts are more evident in the fields of Social Sciences and Medicine. There was dissatisfaction with the traditional indicators like economic indicators in Social Welfare and functional indicators in Medicine, and hence the concept of QOL was introduced (Birnbacher, 1999).

The WHO defines Quality of life as "an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept covering many facets of an individual like the person's physical

health, psychological state, level of independence, social relationships, and their relationship to their environment and spiritual status" (Skevington, Lotfy, & O'Connell, 2004, p.299).

According to the QOL research unit of the department of Public Health Sciences, University of Toronto, Ontario, "The study of quality of life is an examination of factors that contribute to the goodness and meaning of life as well as people's happiness. It also explores the inter relationships among these factors." (University of Toronto)

In this study, quality of life (QOL) of a person is the satisfaction or happiness of that person about different aspects of his/her life. The assessment of QOL was subjective or as perceived by the individual PWD. The QOL was assessed before the disability, after the disability, and after the intervention by VCBR.

3.7.1 QOL measurement

QOL is an important element in evaluation of service delivery programmes. Many studies on the QOL have enabled resource allocation in situations of resource constraints to those programmes that have shown improvement in QOL (Bowling & Brazier, 1995). In the field of health, there are many instruments used to assess the QOL. They differ in terms of content and purpose. Fitzpatrick (1999) has classified the available questionnaires into seven types, which are given in the following figure.

Figure 3.4 Different types of QOL questionnaires and examples

(Fitzpatrick, 1999)

Type of instrument	Characteristics	Example
Disease specific	Assesses QOL in one specific disease	The Arthritis Impact Measurement Scale
Site or Region specific	Assesses QOL in relation to a more specific area of body	The Shoulder Rating Questionnaire
Dimension specific	Assesses a single dimension of QOL such as pain or mood	Mc Gill Pain Questionnaire
Generic	Assesses QOL across wide range of health problems	Short Form of health survey (SF 36)
Summary Items	Single or Short items	Question about limiting long-standing illness in the General Household Survey
Individualised	Assesses QOL in terms of unique priorities of each respondent	Schedule for the Evaluation of Individual QOL (SEIQOL)
Utility	Assesses global preferences	Health Utility Index

Both subjective and objective evaluation of QOL is done in many fields. Objective indicators like quality of living conditions, environmental quality, quality of work conditions, quality of social and health care services, etc and subjective indicators like perception, evaluation and satisfaction, etc are commonly used. The use of subjectively perceived QOL helps in understanding the individual's status and reduces researcher bias.

3.7.2 Domains of QOL

Human beings are multidimensional. The domains of body, mind and spirit all influence the QOL of an individual. Different instruments have been developed that attempt to measure all these domains. However each one has a particular focus and while they have some areas in common, each one is unique and focuses on a particular aspect of QOL.

Gary and Patrick (1999) have developed a balance theory to explain the QOL; according to this theory, QOL is finding a balance between body, mind and spirit in the self and establishing and maintaining a harmonious set of relationships within the person's social context and external environment. The presence of good balance leads to good QOL and absence leads to poor QOL.

The University of Toronto has developed a QOL model and this includes the following domains and sub domains (University of Toronto). (Ref: Fig.3.5)

Figure 3.5 QOL model by the University of Toronto

Main domains	Sub domains
Being (who one is?)	Physical
	Psychological
	Spiritual
Belonging (connections with one's environment)	Physical
	Social
	Community
Becoming (achieving personal goals, hopes & aspirations)	Practical
	Leisure
	Growth

This model of QOL has recognized the influence/importance of the contextual factors of an individual (belonging) and the dynamic nature of his/her existence i.e. about present and future of a person's life (being and becoming).

3.7.3 Generic and Individualized Instruments

The WHOQOL-100 is an assessment tool with 100 items to measure the QOL of an individual. There are 6 broad domains namely Physical domain, Psychological domain, Levels of independence, Social relationship, Environment, and Spiritual domain. Each domain has a series of facets for example the physical domain includes the facets like pain, discomfort, vitality, fatigue and sensory functions. The administration of this tool is time consuming and is burdensome to the respondents (WHO, 1993). Hence, the WHO has developed a shorter version of WHOQOL-100 called WHOQOL-BREF. This has 24 facets of QOL included in the WHOQOL-100 plus two 'bench mark' items from the general facet on overall QOL and general health, but these are not included in the scoring. The facets (24 nos) are grouped under four domains and they are Physical, Psychological, Social relations and Environment (WHO, 1996).

The Medical Outcome Study (MOS) in the United States and the International QOL assessment (IQOLA) jointly developed a short form of health survey called SF-36. The SF-36 includes 36 items and covers 8 domains. They are Physical Functioning (PF), Role limitations due to physical health problems (RP), Bodily pain (BP), General health perceptions (GH), Vitality (VT), Social functioning (SF), Role limitations due to emotional problems (RE) and Mental health (MH). All scores were linearly transformed to a 0 –100 scales with 0 indicating least favourable status and 100 being most favourable health status (Hsiung, Fang, Chang, Chen, & Wang, 2005).

The Schedule for the Evaluation of Individual Quality of Life (SEIQoL) is an interview-based instrument for the assessment of QOL of the individual. This has been widely used with a variety of patient groups, but its applicability may be limited in illnesses, which impair cognitive functioning, or motivational state. The individual should have insight into the factors of his QOL, the ability to think abstractly and the ability to make judgments based on information presented in diagrammatic form (O'Boyle et al., 1993).

Each instrument has both advantages and disadvantages in terms of applicability, usage and elicitation. Some of them are applicable to particular groups of people or conditions but not to others. In reality, although grouping is done based on some common criteria, there are differences found among the members of the group. As mentioned earlier each individual is unique and they demonstrate different behaviours at different times. Using the same tool for people who are different may not always give a true picture of the quality of life. Most of the tools give a composite measure of the QOL, by which an individual/group is classified as having Very good/good/Neither good nor poor/Very poor QOL. This has only limited usefulness because it does not draw attention to the associations between the domains that affect the QOL or the reasons for that particular status.

3.7.4 Selection of tool

The researcher has to decide which instrument will be suitable by considering the research questions and settings in mind. Farquhar and Moray (1995) recommends that 'asking people to describe the quality of their own lives, in their own words, using their own frames of reference will help in clarifying the concept of QOL and measuring QOL accurately.'

The use of SEIQoL in which people are asked to describe their own QOL would help to clarify and measure the individual's concept of QOL but requires a level of abstract thinking which may not be possible with subjects who have poor literacy status. The use of WHOBREF would categorize the subjects into different types of QOL and allow pre and post intervention comparision of QOL. However this may not be adequate for developing a theory of a particular model of intervention programme.

A case study approach would help to clarify the individual's concept of QOL. Additionally it allows deeper exploration of each of the domains of the QOL and facilitates greater understanding of the links between different domains of QOL. In a case study approach, if the researcher proposes to do a semi-structured interview to assess the QOL, it would be advisable to refer to the available QOL

instruments especially the domains and facets covered in the instruments to prepare a checklist. The major domains mentioned in many tools are physical, psychological, economic, social and spiritual. While preparing a checklist or topic guide for the interviews the researcher could refer to these tools and domains.

The case study approach is both a strategy and a flexible research design. Yin (1994, p.13) has defined case study as " an empirical inquiry which investigates a contemporary phenomenon, especially when the boundaries between the phenomenon and context are not clearly evident and when there are more variables than data points and therefore relies on multiple sources of evidence which need to converge in a triangulating manner and benefits from prior development of theoretical propositions to guide data collection and analysis".

3.8 Summary

Research in CBR needs special attention, as there are only few publications in the indexed journals of which, apart from review articles the majority are predominantly experiential. Many articles in non-indexed journals are from grassroots practitioners reflecting the realities of the situation on the ground. This experience cannot be disregarded or underestimated. There are several potential areas of research in the field of CBR such as models of CBR, scope of CBR, volunteerism, sustainability, CBR and the non-disabled community, contextual issues in CBR, empowerment of PWD, and interface between primary, secondary and tertiary care in CBR. The research base of CBR needs to be strengthened, encouraged and made widely available to workers/ researchers in community development and health, and policy makers and rehabilitation professionals. In addition to the scientific community, the research findings should also reach the PWD and other stakeholders in the CBR to enable them to fine-tune their approaches.

CHAPTER 4 THE RESEARCH JOURNEY (METHODOLOGY)

4.1 Introduction

This chapter highlights the methodology and methods of carrying out this study. The researcher's aim was to study the effect of an integrated model of CBR on the quality of life of people with disabilities residing in urban slums, South India. Such research is located firmly within the real world settings of the lives of individuals and practice of professionals. This poses the challenge of evaluating and developing a change in practice. As will be shown, the contexts of individuals and communities varied widely even though they all fell under the heading of PWD in urban slum areas of Vellore. The wealth of information and complexity of the settings were captured using a case study approach. This was preferable to the traditional paradigm of the experimental approach, which would have lost so much rich information in trying to establish a controlled situation. The case study approach represents a paradigm shift (Kuhn, 1962), in which the complexity and reality of the situation was acknowledged. The adopted paradigm of Critical Realism acknowledges the context and its effect on the behaviours of the participants, and as such does not look for causal mechanisms, but for underlying mechanisms within theoretical frameworks that can explain the behaviours and choices in context (May, 2001).

4.2 Developing the Research Methodology

The purpose of this study was to discover the impact of an integrated model of CBR on QOL of PWD. Merely knowing the QOL status does not show the association between CBR intervention and QOL. The question is not only about knowing 'how much' QOL has changed but also knowing 'what' and 'how' these changes have occurred. The case study method allows the exploration of these issues (Robert K Yin, 2003a).

In this case study, QOL of PWD was explored through a series of semi structured interviews based on major domains identified in WHOBREF. The case study facilitated the improvement of the practice in VCBR, and allowed the development of general guidelines and principles of this particular model of CBR.

Although this study was not planned as an action research project, some elements of action research are seen. Robson (2002, p.215) says, "*improvement* and *involvement* are central to action research. The improvement may be seen in the practice, understanding of the practice by its practitioners and in the situations in which the practice takes place." In pure research, the situation is studied without making any changes.

A typical action research methodology follows a pattern of studying a phenomenon, analysing it, reflecting on it and then introducing new action. This pattern is repeated many times over. But this study was planned to evaluate a particular aspect of VCBR. The findings of the study have led to subsequent changes in the way the VCBR is carried out. However the researcher was aware of the possibility of introducing bias and necessary precautions were taken to avoid this.

Quality of life of the PWD was seen as the key outcome for the VCBR. Quality of life assessment tools are widely used in many settings such as Psychology, Sociology, Medicine, Disability and Epidemiology (Verdugo et al., 2005). Initially standardized questionnaires to measure the QOL were explored. There are many tools available to measure QOL in different settings especially for various special groups eg. The Arthritis Impact Measurement Scale. Most of them are standardized and are culturally appropriate. Among them, WHO BREF & SEIQoL were initially considered for use in this study. WHOBREF was considered as it was cross culturally tested in many countries (Skevington et al., 2004) and also the researcher had an experience of using the tool earlier. However since the study needed a rich description of individual QOL with reference to an integrated model of CBR the researcher felt that this tool would be inadequate for the purpose. The advantage of SEIQoL is that it allows the

voice of the individual subjects to be heard. The researcher found this to be a complex tool on pretesting since it requires a level of abstract thinking and good understanding of their own QOL, which was lacking among the subjects in this area (O'Boyle et al., 1993).

But the researcher, from his experience of working closely with the community over the past one and a half decades is aware that

- ✓ each individual is unique and they demonstrate different behaviours at different times.
- ✓ using the same tool for people who are different may not always give a true picture of the quality of life.
- ✓ most of the tools give a composite measure of the QOL, by which an individual/group is classified as having Very good/good/Neither good nor poor/Very poor QOL.
- ✓ currently available tools have only limited usefulness because they do not draw attention to the associations between the domains that affect the QOL or the reasons for that particular status.
- ✓ knowledge gained from people (PWD) is essential for planning appropriate interventions.

Farquhar and Moray's (1995) recommendation of measuring QOL seemed an attractive option. According to them, 'Asking people to describe the quality of their own lives, in their own words, using their own frames of reference will help in clarifying the concept of QOL and measuring QOL accurately'. Hence interviews were used as a major data collection tool within the case study.

4.3 Research Design

A case study design with embedded units of analysis was used within a critical realist paradigm. Elements of action research were inherent within the approach. In this study, the case refers to the VCBR and a unit of analysis will include the individual PWD and his/her immediate family members, the concerned LS and other individuals who played a role in the life of PWD.

4.4 Objectives

1. To generate theory on the value of an 'integrated model' using an educational strategy in the field of community based rehabilitation.
2. To explore the value of secondary and tertiary care services for PWD in a community based rehabilitation programme for improving their quality of life.

Many people who are involved in CBR encourage partnerships, collaboration with other sectors of development, multi sectoral involvement while talking about CBR implementation. For an example, the joint position paper on CBR states that CBR will not work if sectors such as social sector (disability pension, aids and adaptations, vocational training and employment), health sector, educational sector, vocational and labour sector, NGOs and Media work in isolation. It further encourages creating conditions for multisectoral collaboration to advance CBR within community development (ILO et al., 2004).

It would seem that in the context of disability, neither model (medical and social model) provides a complete approach and that an integrated approach, encompassing elements from both models will best serve to meet the needs of people with disabilities, their carers and communities (Cole K, 1999, p.2). This type of integrated approach has been recognized by many individuals and international organizations (Barnes M.P & Ward A.B, 2000b; ILO et al., 2002; WHO, 2001a)

The researcher through this study aimed to provide evidence for an integrated model of CBR which uses an educational strategy.

4.5 Propositions

Within a case study approach it is usual to frame specific statements as propositions to be tested with the multiple sources of data (Yin, 2003). The following are the propositions that form the basis of the conceptual analysis of the data. The first two will be used to explore the effects of an integrated approach on the QOL of PWD; the other two will be used to explore the integration with other services, in particular health. The propositions were:

1 The needs and problems of PWD living in urban slums of Vellore Town can be well understood and addressed appropriately through educating the volunteers (LS) from their own community.
2 PWD and their family will be empowered to improve their quality of life, by which they can perceive changes in their physical, psychological, social, economical, spiritual components and their relationship to the environment due to continuous intervention by LS.
3 The quality of life of PWD in the community can be improved by linking secondary and tertiary care services along with community based services.
4 The quality of life of PWD can also be influenced by other sources in the community, apart from the intervention by CBR.

4.6 Practitioner-Researcher

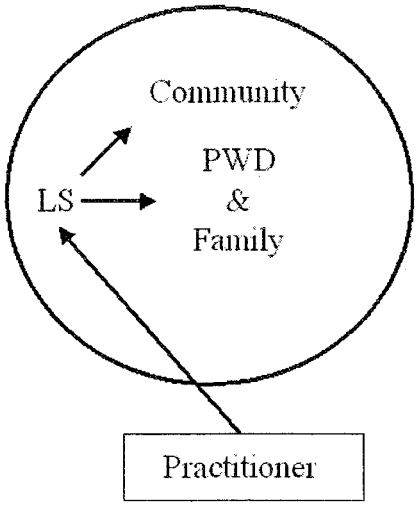
The researcher played dual roles in VCBR as practitioner-researcher. He has been working as Social Worker in the Department of Physical Medicine and Rehabilitation, CMC, Vellore and had experience of working with patients with spinal cord injury/acquired brain injury for more than 15 years. Since 2002, he has been actively involved in VCBR and plays a dual role in VCBR by taking part in the planning and implementation of VCBR (practitioner role) and by being involved in the evaluation of VCBR through his PhD study (researcher role). As described in chapter 2, community volunteers (LS) were selected as representatives from the slum communities. The moment the LS were in place,

the VCBR team including the researcher started working through the selected LS only and never by-passed them during their contact with the slum community. This was done mainly to empower the LS as a valuable resource for PWD in the community. The researcher then played trainer cum managerial role and his contact with PWD in the community was not direct. In Fig 4.1 it will be noted that the practitioner is positioned outside the community context. It implies that the practitioner is not in direct contact with the wider community including the PWD and their family members and that his contact is mainly through the LS from each community. In Fig 4.2 the researcher is positioned within the community context implying that he was able to reach individual PWD for the purpose of the research study. There are both advantages and disadvantages of being a practitioner-researcher when compared with outside-researchers (Robson, 2002). The researcher has been involved from the planning phase of the VCBR, and this experience helped in understanding the ground reality and complex issues of VCBR. Another advantage is that the researcher has access to a great deal of information about VCBR through observation and by compilation from various sources. The researcher was aware of some constraints of being 'practitioner researcher' like the difficulty in balancing time for routine work and research work, hierarchy difficulties within the organization, etc (Robson, 2002). Most organizations expect routine work to be completed before time is allowed for research, thus putting stress on the 'researcher' role of the practitioner-researcher. These expected problems did not affect the study process as the research has been supported by the Institution (CMC), where the project is in operation. CMC is a teaching hospital and committed to the activities at various levels (CMC, 2005-2006). As the allocation of additional personnel was supported by the VCBR, routine work was not neglected.

For the practitioner, contact with PWD and their families was limited. The LS was the mediator between the practitioner and PWD. This was encouraged mainly to empower the local resource person (LS). Professionals from secondary and tertiary centres always contacted the LS in case they needed to interact with any of the PWD. When health camps and other community

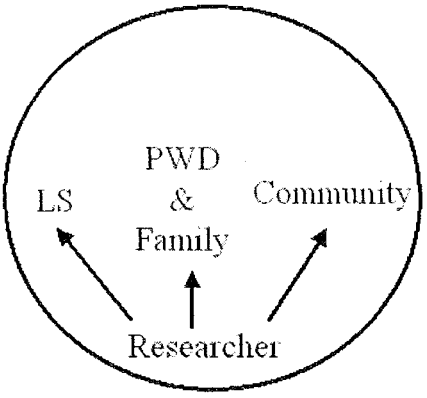
activities were organized, the LS was always the key organizer. (see Figure 4.1)

Figure 4.1 showing Practitioner's position during the reseach phase of the study



This allowed the practitioner to maintain a distance from the PWD, and this in turn helped the practitioner to play his role as researcher effectively without adding bias in the study. It also helped him to avoid prior judgements about their QOL. It enabled him to step outside and view a situation from multiple perspectives. (see Figure 4.2)

Figure 4.2 showing Researcher's position during the research phase of the study



The practitioner-researcher role enabled the researcher to understand the complimentary nature of context and mechanisms in the evaluation. The researcher has incorporated an element of action within the case study. The study findings have helped the researcher to modify the practice. Thus co-learning has occurred during the process of research (O'Brien, 1998). For example, in VCBR, the organization of health camps was not included in the initial plan. At all the community meetings there was a request for general curative health care for everybody in the community. Many of the leaders too conveyed that the general health need of the community was a priority. Considering the felt needs of the wider community and the leaders, it was decided to conduct health-screening camps in all the areas served by the VCBR. Following this decision, many camps were conducted with the support of the local community. In addition to screening for hypertension, diabetes and general health, health education on various public health issues like HIV, alcoholism was incorporated in these camps. A system by which the LS could refer any patients who approached her to the secondary care centre was also set up. Both these modifications were found to be useful for the community whilst not deflecting the main focus on PWD.

4.7 Methods

The use of SEIQoL in which people are asked to describe their own QOL would help to clarify and measure the individual's concept of QOL but requires a level of abstract thinking which may not be possible with subjects who have poor literacy status (O'Boyle et al., 1993). The use of WHOBREF would categorize the subjects into different types of QOL and allow pre and post intervention comparision of QOL. However this may not be adequate for developing a theory of a particular model of intervention programme.

A case study approach would help the researcher to clarify the concept of QOL and measure accurately. In a case study approach, if the researcher proposes to do a semi-structured interview to assess the QOL, it would be advisable to refer to the available QOL instruments especially the domains and facets

covered in the instruments to prepare a checklist. The major domains mentioned in many tools are physical, psychological, economic, social and spiritual. It would help the researcher while preparing a checklist or topic guide for the interviews.

The case study design of this evaluation in a practice based setting enabled the following:

- ✓ In depth exploration of various domains of QOL of PWD
- ✓ Participation of PWD in identifying their needs and problems
- ✓ Wide reporting of disability related issues in the community including customs, beliefs and attitudes of the wider community
- ✓ Free flow of thoughts of PWD because of the semi structured nature of interview and the familiarity with the researcher who is also a practitioner
- ✓ Description of beliefs, customs, cultural and attitudinal issues related to disability

The in depth study of 20 PWD (Appendix 4 for their stories), their immediate family members, concerned LS and others such as a teacher, neighbour or friend, was undertaken (58 interviews, averaging 40 minutes each).

4.7.1 Selection of individual participants (Research Sample)

From among all the PWD identified by the LS in the VCBR area, 20 individual PWD were selected for this study. These were purposively selected so as to achieve representation of the following criteria:

- ✓ Both sexes (Fig 4.3a)
- ✓ Age groups (Fig 4.3b)
- ✓ Marital status (Fig 4.3c)
- ✓ Employment status (Fig 4.3d)
- ✓ Problems of units (Fig 4.3e)
- ✓ Location of intervention (Fig 4.3f)
- ✓ Etiology (Fig 4.3g)
- ✓ Outcome as perceived by the team (Fig 4.3h)

The sampling approach was spread over time, so individual participants were identified in a phased manner using this flexible design. Whilst this approach enabled a broad coverage of the disability spectrum, it is acknowledged that some areas were omitted; for example, individuals with hearing or communication difficulties, due to the problems of eliciting their story through the interview approach. Also, problems of PWD with difficulty in speaking and hearing were not well addressed by the LS due to difficulties in communication. This is clearly an area to be addressed in future work.

Socio demographic characteristics of these 20 individuals are shown in Figure 4.3 (a-h), to illustrate the coverage of the purposive sampling. It should be noted that there is no claim that this sample is representative of the total PWD population in VCBR.

Figures 4.3 a-h showing socio-demographic characteristics of the selected PWD for the study

N = 20

Figure: 4.3 a

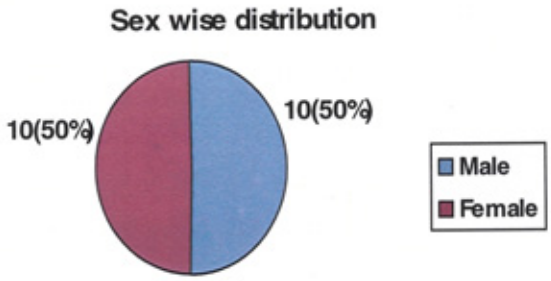


Figure: 4.3 b

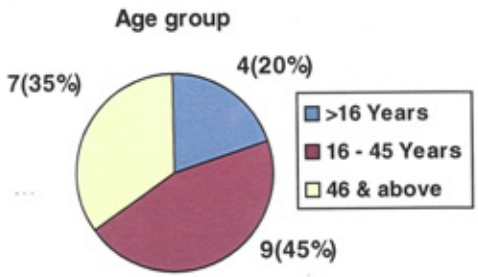


Figure: 4.3 c

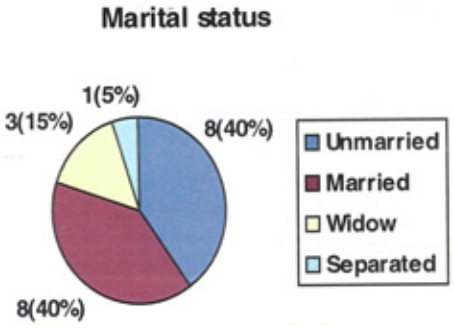


Figure: 4.3 d

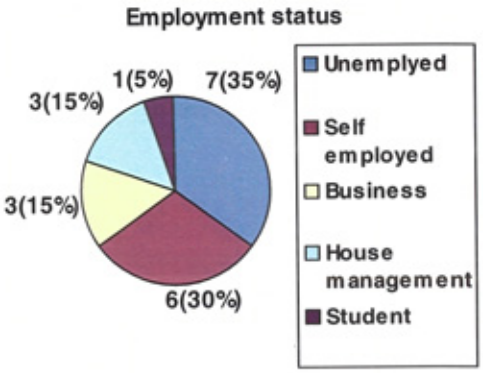


Figure: 4.3 e

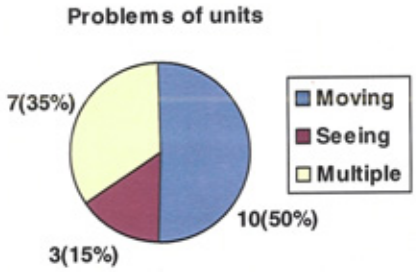


Figure: 4.3 f

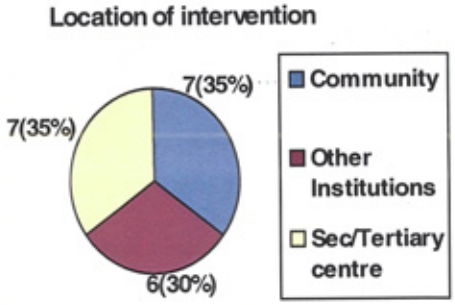


Figure: 4.3 g

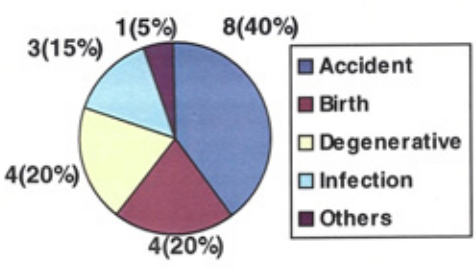
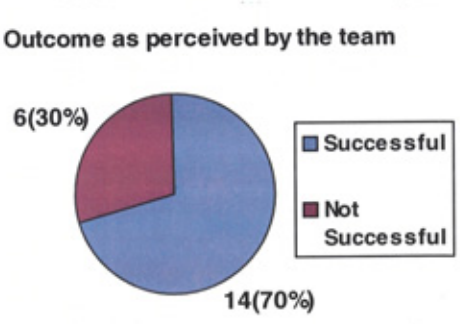


Figure: 4.3 h



4.7.2 Data collection

Multiple sources of data have been used in this study. Semi structured interviews were conducted with 17 PWD directly. Interviews were also conducted with the parents of 3 children who have difficulty in learning. The individual PWD was the first respondent, followed by the family member, then the significant other, and last the concerned LS. The unit of analysis consisted of the individual PWD, the immediate family member(s), concerned LS and in some cases, friends, and others (such as a teacher) who were found to be useful. Fifty-eight interviews were conducted and the total duration of the interviews was 2278 minutes. The researcher had the advantage of local language skills, which helped him to explore the issues in more depth in the interview situation.

All the interviews were conducted using a topic guide based on the major domains of QOL from WHOBREF. Each interview explored QOL at premorbid, postmorbid and post intervention phases of the individual PWD. This was achieved in an informal and flexible way by asking the interviewees to tell their story. The topic guide formed the checklist for prompts to ensure all aspects were covered in the interview (Appendix 5 Topic Guide). Prior to each interview, an exploration of the available information about each PWD was undertaken to ensure the interviewer was aware of the history and key issues.

All the interviews were digitally recorded using a mini disc recorder. The researcher experienced many advantages of using this. They were

- ✓ long duration of recording at a time (maximum of 320 minutes with average quality; 160 minutes with good quality)
- ✓ tiny and so did not distract the attention of the participants
- ✓ good quality digital recording
- ✓ direct transfer of audio file into computer for transcription
- ✓ far more reliable than other audio media such as audio cassette

Given (2004) has recommended mini discs for researchers undertaking qualitative studies.

In addition to the interview information, the researcher used the following sources of information for the study.

1. Observation of performance of the LS in the community
2. Observation of day-to-day life of PWD
3. Documentary evidence such as the project proposal, weekly/monthly/annual reports, review meeting minutes and training reports.
4. Archival data like individual case records of PWD, survey data, referral slips, field visit records, attendance for LS training, pre- and post-test of training, hospital record and school record.

4.7.3 Ethics and Consent

This study was presented to and approved by the institutional review board of CMC, Vellore. Since this is the case study using interviews as the methodology, care was taken to ensure each of the participants understood and gave consent.

Informed written consent is the norm usually practiced with the consent form in the local language signed by the participants before the interview. In the case of participants who are illiterate their signature or thumb impression is obtained after the consent form is read to them and any clarification are made. In this study, most of the participants had poor literacy skills especially reading skills, and were wary about signing forms (in these communities the majority of forms that they are asked to sign are loans or other contracts). Hence written consent was not obtained and instead oral consent was obtained from all participants and recorded with the interview.

Since the researcher is from a large institution with a long history in the area, special care was taken to ensure that those approached to take part in this study did not feel pressurised to agree. All the participants were contacted prior to the interview and the purpose of the study was explained. During the first contact they were informed that the participation in this study is voluntary and they are free to withdraw at any time. They were assured that there will not be

any change in service delivery through VCBR if they decide not to participate. It was also explained that there may not be any benefs to them directly by participating in the study but that by sharing their information, some other PWD may be benefited. They were assured that their identity will not be disclosed in the thesis. In this study, there was a child participant and both his and his mother's consent was sought after explaining the implications of participating in this study.

Oral permission was obtained for use of their photographs in the thesis. The time and venue for the recorded interview was decided together with the participants after they had given their consent. At the start of the recorded interview, their consent was reconfirmed. Of all the participants, only one individual (UN) did not understand immediately why the researcher wanted to record the oral consent. After the researcher explained the reason again, she understood and readily agreed to participate. Special efforts were taken to ensure that the interview took place in an environment that was non threatening and acceptable to the participants. Most of the interviews took place at the homes of the participants.

4.7.4 Transcription and Translation

Initially the researcher himself attempted transcribing the interviews with the assistance of the Express Scribe software. This software is a professional audio playback control software designhned by NCH swift sound software. It helps in transcription of audio recordings by using either keyboard or footpedals (NCH Swift Sound, 1993). However to reduce the time commitment (transcribing one hour audio recordings took 10 hours), an assistant was employed to transcribe the recordings into Tamil All the transcripts were counterchecked by the researcher before collecting text data from the transcriber. One of the Supervisors also randomly checked the transcripts with the audio files for the accuracy.

All interviews were conducted in the language of the participats with which the researcher was also fluent (Tamil). According to Temple and Young (2004, p.168) "the situation where the researcher is fluent in the language of communities she is working with is rare. It offers opportunities in terms of research methods that are not open to other researchers in cross language research. The researcher can use the experience of translating to discuss points in the text where she has had to stop and think about meaning." In the pilot phase of the study, one transcript was translated into English. In this process it was found that some of the phrases could not be translated or translated poorly as they had a specific meaning only in the original language. The following are some of the examples to justify why translation was not done till the data was analysed.

Example 1

While JE's wife was explaining about JE's status following the accident she said,

> "*kaiyil ottamae kidaiyathu...valvasanai kidaiyathu...ellam adangi potchu*".

The above statements cannot be literally translated but the phrases are idiomatic and have powerful meanings. For example if *"kaiyil ottamae kidaiyathu"* is literally translated it means *"no running in the hand"* but the actual meaning is *"he does not have any money"*. Similarly the phrase *"valvasanai kidaiyathu"* has no literal equivalent in English but this phrase expresses that the person's QOL is poor.

Example 2

When VM was asked about how she has been managing her food she replied

> *"since then only MGR rice"*

She was referring to the free noon meal scheme by the state government. MGR stands for Mr. M. G. Ramachandran who was then chief minister of the state who initiated the noon meal scheme. At the time of interview MGR was not alive and many chief ministers have been changed after MGR.

Example 3

AR's wife for a question related to her husband's use of alcohol following medical and rehabilitation care by the VCBR, she said,

"poy aen sollurathu...thanni sapputu iruntha pullu molaichittu irukkum"

The literal meaning is "why should I tell lie. If he had consumed water, grass would have been grown". The literal translation of the word 'thanni' is water but in the context of discussion about alcohol use it refers to 'alcohol'. The phrase 'pullu molaichuttu irukkum' means he would have died and in the place where he was buried grass would have grown.

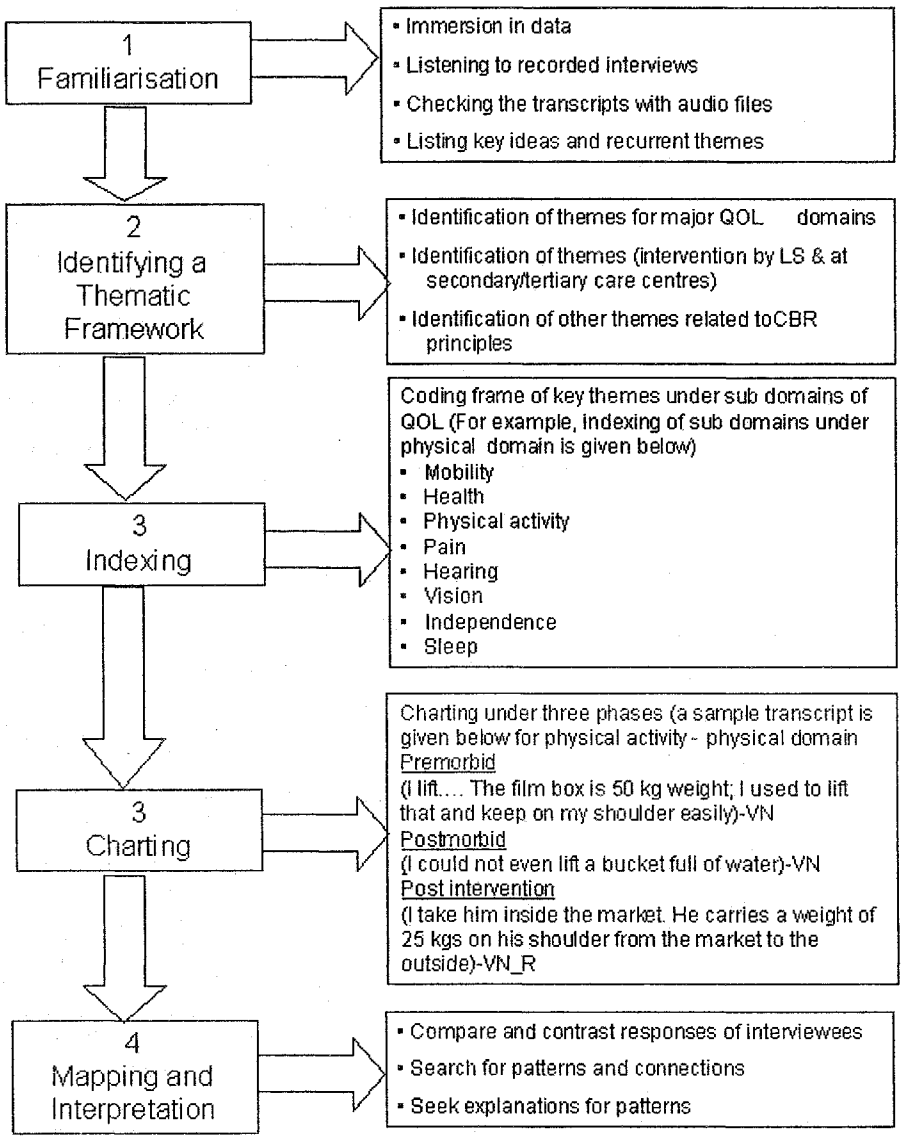
Such loss of meaning in translation would have compromised the analysis of the text and also would introduce an element of researcher bias through the translation (Strauss A & Corbin, 1998; Tenple B & Young, 2004). Hence in consultation with the Supervisors, the researcher decided not to translate the information into English prior to thematic analysis and indexing. It was decided that statements or quotes could be translated if the researcher found it to be useful in conceptual analysis and reporting the data. This delay in translation assured that the respondents' meaning in their own language was retained throughout the analysis process. One of the Supervisors monitored the analysis of data using the Nvivo software in Tamil language. All the translated quotes which were used in the thesis were checked for accuracy in translation by her.

Hence rigor was assured in this process of transcription and translation by independent checking by the researcher and one of the Supervisors. Further the rigor of the analysis was enhanced by keeping close to the original voice of the interviewees (in Tamil).

4.7.5 Data analysis

Qualitative Analysis was undertaken based on the Framework technique (Swallow, Newton, & Lottum, 2003). See Figure 4.4 for an illustration as to how this was applied in this study. The researcher used NVivo QSR software for this purpose (QSR International Pty Ltd, 2003).

Figure 4.4 showing the stages of Framework analysis and an example of its application



4.7.5.1 Familiarization

The researcher listened to 58 semi structured recorded interviews many times before and after transcription done by an external transcriber. While transferring the audio file into the computer, the researcher listened again to the recorded interviews. Following the transcription the researcher and the

transcriber together listened to the audio files and checked the first draft of the transcription. The corrected draft was checked before approval of the final draft of the transcript. One of the supervisors randomly checked the transcripts along with the researcher. All this helped to familiarise the data for the researcher.

4.7.5.2 Identifying themes

Initially the researcher started doing open coding by assigning meaningful topic names (major QOL domains and use of secondary/tertiary care services and other institutions)) to each line of transcribed text. The researcher had a list of domains of QOL as themes and this list was drawn from WHOBREF and used as a checklist. The list of domains of QOL was developed further while doing open coding of each document. For example, physical, psychological, social immediate (refers to family members), social wider (refers to friends, neighbours, social institutions, government, politics), economic, vocational and spiritual domains were listed initially. Leisure and lifestyle domains were added later. In addition to the QOL domains as major themes, the researcher has identified themes related to the use of secondary/tertiary care services and other institutions.

4.7.5.3 Indexing and Charting

All the free nodes were then classified and analysed by axial coding into tree nodes. Following the identification of themes, sub domains of each major domain of QOL were included for coding. Simultaneously the themes were classified under three phases i.e. pre morbid, post morbid and post intervention phases. This formed the tree nodes. Each sub domain at every phase was classified and analysed. While doing this the connections with other sub domains and major domains were also identified.

4.7.5.4 Mapping and interpretation

Analysis of data was done mainly on the various domains of QOL and their association with each other. In addition to this, the role of the secondary and

tertiary care services was also analysed and the next two chapters will highlight the results and patterns and connections between QOL of PWD and the role of secondary and tertiary care centres.

The above analysis forms the basis of the following chapters and was used to develop the conceptual model from themes emerging from the case study.

4.8 Ensuring Rigor

Without rigor, research is worthless, becomes fiction, and loses its utility (Morse, Barrett, Mayan, Olson, & Spiers, Spring 2002). This is particularly so in qualitative research where through the 1980's authors have argued that the concepts of reliability and validity, central to rigor in quantitative research, are inappropriate. Guba and Lincoln (1985) substituted reliability and validity with the parallel concept of "trustworthiness" containing four aspects: credibility, transferability, dependability, and confirmability.

4.8.1 Credibility

Several strategies were used to ensure credibility in this study such as prolonged engagement with the project, persistent observation of dynamics of changes in VCBR, triangulating the sources of information (PWD, immediate family member, concerned LS and others if they played a role), debriefing with peers (weekly discussion with one of the supervisors, annual presentation of status of research in research update at Northumbria). During the transcription phase, one of the supervisors randomly checked the audio recordings with the transcripts. Member checking did not happen due to the educational background of the interviewees. All the raw data including audio files, transcripts, field notes, and documents collected from the individual units in support of evidence are maintained for auditing.

4.8.1.1 Prolonged Engagement

Prolonged engagement facilitates understanding of the culture and ground realities, and builds trust and rapport, which in turn ensures better quality information. The researcher in this study was involved in the VCBR as the co-ordinator from the beginning. Although the VCBR was implemented during 2002 the team had regular discussions about CBR, different models and strategies for several years before that. The researcher was involved in all of the discussions.

4.8.1.2 Persistent Observation

The purpose of persistent observation is to identify those characteristics and elements in the situation that are most relevant to the problem or issue being pursued and focusing on them in detail. In other words the persistent observation provides depth. In this study, the researcher had the opportunity to observe the dynamic changes in the knowledge, attitude and practice of all stakeholders of VCBR including the functional status of PWD.

4.8.1.3 Triangulation

Triangulation is a technique for improving the credibility of findings and interpretation. This term triangulation stands for 'three' as in a simple geometry of erecting a triangle using antenna to receive signals from three directions. However in real world research the researcher is encouraged to use multiple sources/methods of evidences and multiple investigators are used to study the same phenomena. According to Robson (2002), triangulation was adopted at various levels to validate information and to improve the quality of data. Interviews have been conducted with 3-4 people around each PWD, which allows for confirmation of data. In addition to conducting interviews, other methods of data collection were adopted to further confirm these data, these included observation, referring to documents, and notes of meetings.

4.8.1.4 Peer Debriefing

Peer debriefing is a process of exposing oneself to a disinterested peer in a manner paralleling an analytic session and for the purpose of exploring aspects of the inquiry that might otherwise remain only implicit within the researcher's mind. Meeting with one of the supervisors every week and the principal supervisor once in six months helped to clarify some issues related to researcher bias. The researcher presented the ongoing findings at a number of meetings and seminars and gained valuable feedback from his research peers. The formal progression stages of the research also provided valuable opportunities to present and defend the research decisions and approaches.

4.8.1.5 Negative Case Analysis

Negative case analysis is a process that explores the data for contradictions in fact. It seeks to propose a rival explanation for a fact till none are found within the data (Robson, 2002). It can also propose a process or a theory different from the original theory. It might discover a force larger than the project's boundaries or social trends, which might provide rival explanations to the observed fact. A full exploration of these possibilities will make the process of negative case analysis improve trustworthiness in research design (Yin R. K, 2003). To reduce bias, the researcher has selected units from both successful and not successful PWD as assessed by the VCBR team.

4.8.1.6 Member Checking

Member checking is one of the techniques for establishing credibility in which the data, analytic categories, interpretation and conclusions are tested with members of those stake-holding groups from whom the data were originally collected. This was not possible in this situation where the participants had poor literacy status especially in reading skills. One of the supervisors checked audio files and transcripts at random.

4.8.2 Transferability

External validation is a process of strengthening the generalizability of the findings in research. It has been suggested that the term 'transferability' is more suited to qualitative research as the term generalizability has come to mean a statistical 'fit' between the sample and the population from which it has been extracted. Transferability suggests that the processes discovered in qualitative research can be expected to replicate themselves in similar circumstances. Thus case studies rely on 'Analytical Generalization' rather than statistical generalization (Robert K Yin, 2003a). In this study purposive sampling was done in order to support transferability. By undertaking an in depth study based on 20 PWD, the researcher was able to provide a thick and rich description of the phenomena in play. The findings cannot be generalized, but the basic principles / philosophies emergent from this particular model of CBR practice can be explored in other contexts.

4.9 Boundaries of this study

The study population identified above did not include people with difficulty in understanding and people with difficulty in speaking and hearing. This was due to the problem of conducting in depth interviews in these cases. In consequence the results of this study cannot claim to represent these two groups of PWD. However the general principles identified in the study could be explored in these groups at a future date.

4.10 Overview of presentation of findings

The findings of this study will be presented in 3 chapters (5, 6 & 7). In chapter 5, the findings related to the QOL of PWD are presented. The role of secondary and tertiary care in CBR is presented in chapter 6 and the findings related to the integrated model of CBR are given in chapter 7.

CHAPTER 5 FINDINGS – QUALITY OF LIFE OF PWD

5.1 Introduction

In this chapter the findings relating to the expressed QOL of PWD who were helped by interventions carried out through VCBR are presented. The Quality of Life of PWD was the main indicator used in this study. However QOL is something, which is experienced by individuals. Confining the measurement of QOL to objective, quantifiable measures results in the loss of valuable information, which is subjective or dependent on the individual's perception. The use of semi-structured interviews allowed the PWD to express issues pertinent to their QOL in their own words. Whilst the interviewees were guided through a range of topics, the emphasis placed on each area was determined by the interviewee not the researcher. The presentation of the findings is based on the major QOL domains of the topic guide. These domains formed a-priori themes in the analysis. Within each of these domains a range of emergent themes were identified. The volume of discussion around each theme reflected the importance and relevance of that theme to the individual, for example approximately 50% of each interview centred on issues around the physical domain, whereas, in spite of prompting, the concept of leisure and leisure activities was largely alien and hence sparsely discussed. Given the context of these PWD, who were largely engaged in manual work and in poverty, this balance is not suprising. Within each domain a rich description of the PWD's lives and context is presented and the impact of LS intervention explored.

Each individual is unique and his/her perception of quality of life (QOL) is different. Attempts have been made in various fields to define and clarify the concept of QOL. This has been a challenge because of the multidimensional and complex nature of an individual's life. The multidimensional aspects include the person's physical health, psychological state, level of independence, social relationships and spiritual status (WHO, 1998).

In this study, a 'case study' approach was used to explore the subjective QOL of the PWD. The propositions that arose from this approach provide the framework for the interpretation of the findings.

They were:

1. The needs and problems of PWD living in urban slums of Vellore Town can be understood and addressed appropriately by educating the volunteers (LS) from their own community.
2. PWD and their family can be empowered to improve their quality of life, by making changes in the physical, psychological, social, economic and spiritual aspects of their lives as well as their relationship to the environment because of intervention by LS.

The presentation of findings which follows is structured around the major domains of QOL which are physical, psychological, social, economic, leisure, lifestyle and spiritual domains.

5.2 Physical Domain

The physical domain has a significant place in quality of life assessment. It focuses on problems related to the structure and functioning of the human body. In this study the physical domain was found to have links with other domains like the psychological, economic, spiritual, and vocational. Any attempt to address the problems of an individual without considering the physical components such as pain and mobility will be incomplete. Turmusani (2004) remarked that feminists and postmodernists who support the emancipatory approach for disability research have neglected the experiences of the body and pain. PWDs in different parts of the world are found to experience similar bodily problems.

In this study, mobility, physical activity, Dependency, physical illness, comorbidity and health needs, pain and sleep were the emergent themes, which were found to be associated with disability. Each theme is presented and

explored using examples and quotes from the interviews and briefly summarized at the end of the section.

5.2.1 Mobility

Here, 'mobility' refers to movement of a PWD within his/her home environment and outside. It does not include community reintegration and socialization.

The researcher is from a rehabilitation institute for persons with physical disabilities, where mobility for PWD is emphasized. Many people with paraplegia are vigorously trained to walk with leg braces and elbow crutches (Werner, 1998a). Whenever it is not possible to retrain their walking, they are given mobility training in the use of a three-wheeler or a wheelchair. Mobility is seen an important element for PWD as it facilitates their entry into the mainstream of society and also exposes them to the resources in the community.

In this study, walking, riding a bicycle or motorbike were the most common modes of mobility prior to acquiring disability. Walking was mentioned by many PWD very often. Walking was considered a normal activity among people in the VCBR coverage area. Though the slums are located in the middle of the town, people need to walk to be able to carry out several activities like going out for toileting, seeking work, shopping, attending schools, visiting hospitals, movie halls and religious institutions. In an emergency and in rare situations, people hire auto rickshaws. One of the individuals (JE) mentioned very proudly that he has walked up to 32 kilometres to see a movie despite the availability of transport for him at that time. In his words

"Yes I walked up to Kannamangalam to see an MGR movie... "

He considered this an achievement.

The degree of mobility among PWD was varied, for example: some were bedridden, some could not walk, some walked with support, some moved by bottom shuffling, others by kneel walking. Imperfect (abnormal or defective)

walking patterns, restricted hand function and the need for support during walking were not liked by some PWD.

According to RA

> *"How can I visit the temple when I can only walk on my knees? ...I won't go."*

VI reflected a different point. She said,

> *"I can't lift my hand on my own to worship...only with the support of the other hand can I lift this hand (implying God did not help)...I felt let down...I stopped worshipping God."*

There was a case of refusal of 'supported mobility' for attending a social function. VM had a fractured femur, and was immobile for some period after the accident. Her relatives offered to carry her to attend a family function, but she refused the offer, as she did not like being carried.

Impairments such as bone fractures, loss of vision and pain were reported as the reasons for mobility restrictions. UN is a lady who had difficulty in seeing said that

> *"I won't go out of house after 5.30 or 6 pm (dusk)...it will be a problem...If I want to go out, my son would take me by his cycle".*

Many individuals discussed interventions and outcomes introduced by the LS. These included sitting and standing up, walking with the support of a person/wall/stick, walking within parallel bars, movement of limbs, independent walking to a long distance and cycling. Most of the interventions took place within the community, except in the case of two individuals (AR & JE) for whom some part of the interventions took place at the secondary care centre. Interventions included physical exercises taught and carried out by the LS, supply of aids and appliances like axillary crutches, walking sticks, height corrected footwear, and wooden parallel bars made for the purpose of training at the individual's home. Locally available resources (materials) were used for mobility training For VM and RA, old sarees hung from a beam were used by the LS as a support to help them stand up from a sitting position (similar to the idea of a monkey pole). Wooden parallel bars were arranged for AR and RA at their homes.

(RA) said,

"Because of training with the saree, I could take few steps".

The LS who worked with AR commented

"I have asked the older neighbours to help AR with walking...they collected bamboo poles, rope and they themselves fixed the bars on the ground...AR practised walking for about 6 months within the parallel bar and then stopped because of improvement".

Mobility aids, which they received through the VCBR, were found to be an attraction for PWD. AR's wife felt the main reason for improvement in mobility was the free supply of crutches by the secondary care centre. The supply of crutches had a role to play (with) in AR's mobility, but the considerable amount of local resources used and AR and his wife did not perceive the improvement of mobility gained through this means as significant.

Clearly the use of locally available cost effective materials and the participation of the community contributed to the successful rehabilitation of many PWD. One of the main principles of CBR is using the locally available resources (Helander, 1992). In VCBR, the importance of local resources was seen through local people's participation in the rehabilitation training and the use of available materials. The VCBR team played a key role in incorporating local resources in the rehabilitation through training and encouraging the LS. The response of AR's wife illustrates the need to promote the use of local resources in the rehabilitation process. David Werner (1998a) has promoted the use of local resources by the PWD. Identification of local resources according to the needs, awareness creation about the local resources in the public and helping PWD and their family members to understand the value of local resources are some of the strategies that can be used.

However the CBR team should not be dogmatic about the use of local resources. For example in VCBR, the team made a child walker with bamboo for a child with difficulty in walking. This was found to be more expensive than a wooden walker available in the market. This showed that sometimes, external resources may be more accessible and less expensive.

Intervention in one area affected other aspects of individual PWD. For example VI said,

> *"After Mary Amma's visit....she has given exercises....now I can move my limbs to some extent....I could come out of my home and visit the neighbour with the support of a stick...it helps me to ventilate my burden (this is a strong expression in Tamil relating to relieving an emotional burden)...like that I pass my time..".*

It is clear that the physical improvement seen has positively affected VI's emotional wellbeing.

The rehabilitation of VN validates the educational approach in VCBR. The description of various exercises learnt and phases of improvement described by VN demonstrates the significance of the LS's role and her therapeutic skills. In addition, cooperation by VN was also evident from the same description. In his words

> *"then she asked me to do exercise...step by step...first of all.... slowly...by sitting and standing...standing with one leg...holding and bending the leg while lying down...she taught...I was doing that...Now it has become normal step by step; that is...I still cannot bend the knee a little bit...otherwise, it is comfortable for walking".* Also
>
> *"Initially...with support...that is one stick and someone to come along for support.... then step by step by doing exercise, I started walking with stick.... now I can walk independently".*

His walking improved with the intervention by the LS and he started riding a cycle on his own. He said

> *"I ride a cycle (smile)...some people are telling me not to ride a cycle... for me...what the interest I have is...I ride the cycle with an interest and idea of going back to the previous job".*

But he also felt that his current mobility would not be sufficient for a job that requires heavy physical activity. VN initially approached the concerned LS for a referral to the secondary/tertiary care centre for his problem with mobility. But the LS examined him and started teaching both VN and his wife some exercises, which she learnt through VCBR training sessions. This showed that the persistence, patience and skill of the LS in directing his rehabilitation

enabled him to achieve considerable improvement in function. This illustrates the strength of the education-based approach of VCBR (training of LS) and the community based intervention. This principle was evident in many other cases in VCBR.

In summary this population relies heavily on mobility for daily tasks, intervention on mobility through VCBR demonstrated a direct improvement and had profound effects on the overall QOL. The examples above show in addition that improved mobility has impacted on social reintegration, happiness and vocational resettlement.

5.2.2 Physical activity

Day-to-day activities of an individual depend on the roles and responsibilities they have at home and in the workplace. Traditionally, men look after the financial needs of a home by going out for work and women stay at home taking care of household affairs. But the trend has changed over the years. In addition to taking care of family affairs, women have been going out for work to meet the financial needs of the family. The burden they face everyday has been increasing significantly and should they acquire a disability, their problems are multiplied. VM described her normal day before she acquired disability like this,

> *"I used to wake up by 5'o clock in the morning...immediately I sweep the entrance of my house, draw a kolam (drawing which decorates the ground outside the house made with lime or rice powder) and then clean all the vessels. After bathing, I go out for fetching water and then I give bath to my children, wash their clothes and then take them to school. If my husband was around, I organize everything for him and then I have my breakfast. Then I go out for shopping and come back and cook meals. After cooking, I wash more clothes and have a nap. By 4 pm, I make coffee for my husband, and then sweep the areas outside again, washing the vessels, which we used in the afternoon and fold the washed clothes. By the time I finish cooking the night meal it will be 9pm"*

This shows the significant role of a woman in an Indian home. Considering the amount of responsibilities, there is no doubt about the effect on the whole family following the individual's disability.

In contrast, the area of maximum physical activities for men was outside the home, often related to their work. Two male PWD discussed their physical activity in terms of lifting heavy weights (loading and unloading of heavy objects) JE said,

> *"I could lift and load a 100 kg bag easily"*

VN said

> *"I lift...The film box is 50 kg weight; I used to lift that and keep on my shoulder easily"*

A good physique was required to fulfil the demands of heavy manual work and the disability had a huge effect on the PWD's capacity for heavy manual labour. VN, who was active and strong before acquiring a disability, reported his status after the accident,

> *"I can't even lift water...during that time, I could not even lift a bucket full of water"*

The sudden change in their status from independence to being unable to do their normal activity affected the individual drastically.

In this study, it was found that when the male member in the family acquired a disability, the women were skilled in managing both household and economic activities. However men found difficulty in managing the household activities when the female member in his family acquired a disability. Usually some other female family members take on the role of caring for the PWD as well as managing the household activities. If there are no other female members in the family circle, the family continues to search for an alternative female carer outside the immediate family circle. In some cases like in VI's family, the family members started looking for a bride for the elder son to take over the carer's role within the family. This showed that the pressure/burden for a woman either as a PWD or as a carer was enormous compared to that of men.

Any CBR programme should consider the family situation and role of the family members especially the differing roles of men and women when planning an appropriate intervention. As the needs and problems of women with disabilities are different from men with disabilities, any intervention should pay special attention to both women with disabilities and female carers of men with disabilities.

Disability that was acquired later in life had a more profound impact on an individual than that acquired at birth or since childhood (Bishop, 2005). In this study, PWD, who acquired disability early in their childhood or were born with a disability were able to manage their physical activities better. For example KB, who had difficulty seeing since childhood said,

"I cook food...if somebody sits with me...I cook food".

In this study, we found that adults who (had) with a disability since childhood had adapted to their disability and modified their functional activities in such a way as to be independent. However adults who acquired a disability later in their life, regardless of whether the disability was temporary or permanent, found it difficult to adapt to the sudden changes in their lives and their dependence upon others.

There were several instances of improvement in function in daily activities by PWD following the intervention for mobility through LS/VCBR. For example, DE who had two falls and each time broke her upper limb mentioned that she had difficulty in doing routine household work and beedi work. After intervention by the LS (exercises) and the team members (referral), she was able to substitute as a housemaid for her sister during the time when her sister was not well. In her words

"when Akka (elder sister) said that she was not well, I went to the house where Akka was working as housemaid, cleaned all the vessels, swept all the rooms, washed all the clothes...I could do that much"

In some instances the LS intervention achieved both an improvement in function and led to a real change in the functional status, in others whilst

function improved no equivalent change was seen in status. This is illustrated through the voices of the individuals below:

EL reported that she was dependent on others for physical activities like toileting, bathing and washing clothes because of her disability (prior to the intervention by the LS). She was unhappy with her dependent status. After intervention by the LS, despite some residual impairment, she could manage her own physical activities like fetching water, going shopping, washing clothes, toileting and bathing.

VN reported that he could not even lift a bucket of water before intervention. His wife remarked that after intervention,

> *"I take him inside the market to do the wholesale purchases. He carries a weight of 25 kgs on his shoulder from the market to the outside..."*

For VA, the intervention did not stop her tremors completely but there was some improvement. Though several efforts were taken at all levels like LS intervention at the community, investigation done at tertiary care centre and regular treatment offered at secondary care centre she was not happy about the improvement. The concerned LS perceived some improvement, but VA and her neighbours could not see this. She said that she gets upset by the comments of the neighbours about her tremor despite having regular treatment.

> *"there is a person called Kala....once she taunted ...'having injection every month....still getting tremors while carrying even a small vessel'...I get upset and return home".*

The intervention on mobility for people with difficulty moving showed good results for many individual PWD. In addition, intervention focused on mobility showed improvement in other areas like functional independence in doing their activities of daily living and helped them to enlarge their social network. Mobility in this study refers to mainly 'walking with or without support' and in some cases using a tri-wheeler or a wheelchair. Special attention was given to training to walk with or without support wherever possible, as the physical environment (terrain) was not disabled friendly. In developed countries training

for wheelchair mobility predominates, as the physical environment is disabled friendly. But in countries like India where most physical activities have to be carried out while standing and walking, a special focus on training PWD to walk is required.

In VCBR coverage area, the majority of the houses do not have toilets. There are public toilets built by the government, which are not disabled friendly. A majority of people use the open field for toileting/defecation. Disabled friendly public toilets in each community would help not only the PWD but also the elderly.

In summary, physical activity is reduced by disability. For women, this restriction may have a greater impact due to their expected roles and responsibilities. Intervention, which enhanced mobility, had an indirect impact on physical activities pertaining to home making and vocational roles.

5.2.3 Dependency

The ability of individuals to look after their personal needs is a skill developed early in life. Obviously a child is dependent on a carer for his/her self-care activities. When the child becomes an adult, he/she becomes independent in self-care activities. The dependency status of a child with disability and an adult with disability is viewed differently. For an adult with disability, the learnt skill for self-care is commonly challenged following an accident or event, which results in disability.

Many PWD reported their lack of independence following disability mainly in the area of self care i.e. activities of daily living such as toileting, bathing, eating, dressing, fetching water. Some individuals reported partial dependency for toileting, walking and cooking. The lack of independence made them feel unhappy and sometimes they became irritated about the condition. The immediate family members generally took on the responsibility of supporting the PWD. There was evidence of support from neighbours too. No one liked to

be dependent on others especially for day-to-day activities. This is illustrated below.

KB is a lady with total blindness who was upset about the dependent nature of her condition (especially bathing and dressing) and complained

> *"Why am I like this...if someone says anything (refers to her dependant status)...since I am in this condition I am dependent on others ...why God made me...?".*

SK is a boy with multiple problems living with his brother and father. His father who is a divorcee explained about his son's dependent nature and how he managed the dependent child and his work. He is a shoemaker and has to go out for his work. His son SK has severe disability due to mental retardation and is totally dependent on others for all activities of daily living. The researcher observed SK's living conditions and found that SK was in a very pathetic and insecure living environment. He was like an animal tied to a pole and left alone with some food next to him. By the time the father returned home, SK would be in a mess with urine, stools and food all around. SK's father said,

> *"I tied him with a rope...on the pole...tied him on the pole...small knot only...he does not have the ability to remove the knot...otherwise he will go out...he will come out.."*

This child was not aware of his own condition and that the way the father handled him was ethically questionable. From the father's point of view the child would be safe and secure if restrained. If not, the child would go out and hurt himself and be hurt by others. The efforts of the VCBR team to make this child independent failed as the child had severe cognitive and communication impairments. In consultation with the father, the child was admitted in a residential home through VCBR. Whilst this intervention was not based within the community, and hence outside the normal boundaries of CBR, the outcome was to secure the safety of the child through the provision of residential accommodation. It could then be argued that such an action could lie within the remit of CBR and it served the best interests of the child and the community.

Parents of children with severe disability normally experience stress when their children are totally dependant on them for all activities of daily living. It is more difficult for single parent like SK's father. It was found in the Guyana project that poverty was the main reason why children with disabilities were left alone at home as this enabled the parents to earn (O'Toole & John, 1991). Parents often have to give up their personal interests. They have problems in fulfilling their social responsibilities at work and in their social lives e.g. participating in wedding ceremonies of close family/friends. Several NGOs and parents of children with severe disabilities are trying to address some of these problems.

For example (Ref Box 8.1 in page 191), day care centres where children with severe disabilities are cared for help the parents to be free at least during the daytime.

There was evidence of improvement in the independence of some PWD who were earlier more dependent. The most frequently mentioned areas of independence were toileting, bathing, dressing, fetching water, washing clothes, combing hair, eating and moving around. There were three individuals who said they had achieved more independence on account of the VCBR. For example DE said that she had become independent to the extent of helping others and in her words

> *"now I can manage toileting on my own.....with exercises, I could bend my hand...I could take bath on my own...I can't do with this hand....I take bath on my own...I manage my toileting...I don't need the help of any other person for any of my work sir....yes...I can help others with this hand...."*

RA's grandmother when asked about the training given by the LS related to toileting, said

> *"now only....one year...two years...she washes her bottom...I used to do that...she can do herself...after training...she washes herself....all these because of that lady...taught by Aji (LS)".*

Despite strong family support, VN felt uncomfortable about his dependance on his family members especially for toileting and said

> *"They made to sit there (in the toilet)...then my daughter will go away...my wife will stay with me till I finish (toileting) and she only washed my bottom...I cannot do it with the straight leg, I cannot do...I was like a child...that situation...Even a child would have been in a better position...my condition has become like that".*

Following intervention by the LS in the area of mobility he became independent in his self-care. VN proudly said

> *"Yes it has helped ...now...since Ammu has given exercise for mobility, I carry water for bathing; I carry water for toileting; If the people at home go for collecting water, I bring a vessel (kudam); I pump water for them; this has helped in many ways; If I want to go to a shop, I go and come back".*

There was only one individual (VM), who did not perceive any improvement in her independence although the LS could see distinct improvement in her mobility, which should have contributed to her independence.

In summary it is shown that lack of independence, particularly in the areas of self-care although rooted in a physical problem, also impacts widely across the other domains. As a consequence physical interventions around mobility also addressed these issues and had much wider benefit empowering PWD in multiple domains. However not all aspects of physical problems have been addressed.

5.2.4 Physical illness, comorbidity and health needs

This study has identified a complex relationship between disability and individual health status. Alcoholism, HIV/AIDS, accidents, hypertension, stroke, diabetes, that are commonly prevalent in the community, act as predisposing factors for disability. For example, JE's fall was caused by excess use of alcohol, but he does not seem to have realised the ill effects of consuming alcohol.

He proudly reported,

> *"I never fell sick because of the drinking habit. I never attended any hospital"*

VN reported in the past that he had had typhoid and work related injuries while working. As a result he could not go to work for 7 months. The nature of his work (climbing on top of buses with heavy loads on his head) was a definite risk factor both his earlier and current impairments had been sustained, as a direct result of his work, but his perception of risk was low. In another instance of the association of disability and general health, VI said,

> *"till 43 years, I was healthy...since my husband's demise...due to increased stress, my blood pressure has increased and resulted in this condition"*

In this study, it was found that there was poor health awareness, lack of access to health resources and insufficient knowledge of occupational hazards among the PWD interviewed. Many individuals reported that accessing a health care institution for their disability helped them to discover other co-morbidities. Of these, some of the conditions had a direct association with their disabling condition and some did not. For example AR did not know that he had tuberculosis till he was picked up and referred by the LS to the secondary care centre for difficulty in moving. JE was not aware that he had diabetes and hypertension till he was admitted at the secondary care centre for difficulty in moving.

From the interviews, it emerged that the lack of awareness about early symptoms for certain health problems, and the lack of a proper approach to the investigation and treatment were issues that needed attention. For example, UN said,

> *"first I had headache...very first headache...I started buying tablets from the shop...I buy from the medical shop at Dinakaran bus stop and consume two or three tablets...I take a tablet when there was head ache...there was no time plan...it resulted in peptic ulcer...peptic ulcer....because of peptic ulcer....I was not hungry....if I eat... I had nausea...if I belch after eating...my abdomen will pain a lot".*

The practice of self-medication is common among people in VCBR coverage area. The reasons could be lack of finance and lack of time to go to a health care facility for a proper check up. They are not aware of the seriousness of consuming heavy doses of medicines without medical advice. They seek proper medical care after the problem became more complicated and unbearable. By the time they come to a health care institution, their main problem has often created lot of other problems.

There were three individuals (AR, JE, VA) whose health problems were investigated and a final diagnosis made at the secondary and tertiary care centres. Tuberculosis, diabetes and Vitamin B-12 deficiency were the identified medical problems and appropriate treatment was initiated and regular monitoring and follow-up were done through the LS. AR, who was diagnosed to have tuberculosis, completed his treatment with the support of the LS. The LS undertook to deliver the anti TB drugs regularly at AR's home. JE was referred to a general health screening camp held in the community by the LS. At the camp he was diagnosed to have diabetes and was admitted at the secondary care centre and where his blood sugar was brought under control. Considering his poor economic status he was helped to get free drugs from the government hospital. However he was not satisfied with the quality of the drugs and started buying the drugs from a medical shop; they were paid for by his mother. VA had thorough investigations done at both the secondary and tertiary care centres and Vitamin B-12 deficiency was identified as the possible reason for her tremors. Treatment was initiated at the secondary care centre and followed up regularly in the community by the LS.

PWD have poor access to health care resources for various reasons. Mobility restriction, the need for additional persons to accompany a PWD, the need for special transport arrangements and the financial implications are some of the reasons for poor access. If the community has poor access to general health care resources in the first place, special priority is not given to PWD for general health care. In VCBR, a referral system has been developed to address mainly the general health problems of PWD and also the wider community. Turmusani (2004) recommended that health problems of PWD especially their

pain should be addressed in order to achieve their full participation in community life.

In summary two main aspects of general health related to VCBR are seen as important. Firstly, promotion of better health through awareness and secondly, identification of need and appropriate treatment at the local level or referral to secondary or tertiary centres for general health problems.

5.2.5 Pain

Various aspects of pain experienced by PWD, which included their suffering, coping strategies, methods of management and intervention by the VCBR were discussed. Whilst pain was clearly within the physical domain, its impact was seen across many other domains. Pain was seen as a barrier to full community participation.

The severity of physical pain had significant effect on two individuals (HB & VA) and they both experienced unbearable pain. HB expressed that 'it is better to die than living with pain'. In his words,

> *"it is paining...during that time...I feel like jumping into a well and dying".*

VA had experienced severe pain and remarked,

> *"while I go to the toilet, both my legs are paining...if I sit on a high level...I could not spread my legs...paining severely...back is aching while I am idle".*

There were several pain management techniques adopted by PWD. JE used to consume alcohol to control his chest pain. In his words,

> *"my health was also affected...I had chest pain. The pain subsided by the consumption of alcohol. If not, I had the pain. (Cough)...I used to sleep under the influence of alcohol."*

There was evidence of management of pain by self-medication, which resulted in other complications. For example UN whose words are given above (see 5.2.4) developed peptic ulcer disease following self-medication for pain.

This study showed how the PWDs' pain affected other aspects of their life. For example, headache affected AN's studies at school, pain in the limbs affected mobility for EL, VM and VN and toileting for VA.

AN & UN, both of whom had reported headache earlier, said that they got rid of pain following intervention through the VCBR. AN's teacher said that after using spectacles, his studies were not affected any more and in her words

> *"after using spectacles he started doing his own work...he is studying...he is good at reading all...he is attending to his work automatically"*

UN expressed that

> *"my vision is very clear since few days...there is no fault with eye...no headache now...there is no headache at all...I have stopped all the tablets"*

Another individual (DE) used an adaptation for doing her work and also managed the pain simultaneously. DE had a fracture of an upper limb and was given a splint. The splint helped her to control/manage the pain in the limb but restricted her hand movement for beedi work. She said,

> *"If I do the packing work of beedi I develop pain sir...even today I have done that work...when I do the work I keep the belt (splint) aside...do the work swiftly...then immediately I put on this belt (splint)...pain stops completely"*

VN expressed that his pain was controlled by regular exercises taught by the LS and in his words

> *"Because of exercise only, my pain was reduced; I started walking; I could bend and straighten my legs; I could feel the improvement while I was doing the exercise"*

There was one individual who was not satisfied with the pain management by the VCBR. JE complained about pain and he said that he was not happy about the pain management at the secondary care centre. At the secondary care

centre he was discouraged from taking painkillers on his own. This upset him. But the pain was his main concern. In his words,

> *"earlier that Dr. Amma gave me some medicines for the pain relief. Now there are no medicines and nothing...that is why I feel little? pain; I struggle to walk and that is why, I lie down in the cot and go to latrine. Next day, I go to latrine and wash my face and brush my teeth and return. If I am awake in the evening, I used to sit and because of severe pain, I could not manage and lie down...I could not lie down in the night...I found it difficult to sleep. If I sleep, I feel pain in the bones... feel like I have been beaten....If I walk, it is interfering. I cannot sit like this. If I sit, I get pain. If I take some tablets...pain is reducing, I am able to sleep. But Amma / Doctor said that I should not take tablets..."*

Pain was a significant component of the physical domain, which affected many individuals. It affected many domains like work, physical activity, emotions, and mobility. Intervention aimed to reduce or manage the pain seems to have yielded a good outcome in other domains. For EL, the LS was sensitive in understanding her pain while teaching some exercises for mobility. But when the pain did not subside and was hindering the treatment, the LS referred EL to the secondary care centre. She was sensitive to her poor financial status and recommended free treatment. The pain was reduced following medication. This allowed the LS to continue the exercises with the EL. This in turn has helped EL to stand and walk.

In summary although pain is discussed as a physical phenomena its impact is seen across a number of domains. Different strategies such as teaching exercises, referral to secondary care centre, splinting, prescribing drugs were used for pain management in VCBR. Despite adopting several strategies, some PWD were not satisfied about their pain management.

5.2.6 Sleep

Sleep is a minor emergent theme reported by three individuals (HB, JE & VM) who had problems related to sleep after disability. Sleep problems were

associated with pain, concern about the future and ill health. JE's problem with pain was not sorted out even after intervention from the secondary care centre. Pain seems to have affected his sleep and in his words

> *"I could not lie down in the night...difficult to sleep. If I sleep, I feel pain in the bones... feel like I have been beaten ..."*

Only one individual (VA) reported that she slept well at night inspite of her disability. The others did not identify sleep as an issue.

5.2.7 Summary of physical domain

Among various facets of the physical domain, mobility, activities of daily living and pain were found to significantly influence the lives of many PWD. These facets were found to be closely related to one another. Improvement in one facet led to improvement in other facets as well. Improvement in physical domain as a whole led to improvement in other domains like social, psychological and vocational.

The QOL of PWD was also influenced by the general health status. Lack of care for the general health conditions like fevers and respiratory infections affected the QOL of PWD. In some cases this led to further deterioration of disabling conditions of PWD, which in turn affect their QOL.

5. 3 Social Domain

The social domain has two major subdomains. They are the immediate social domain and the wider social domain. The immediate social domain includes the individual PWD's family and the dynamics within the family in relation to the disability and rehabilitation. The wider social domain includes neighbours, friends and other community members.

5.3.1 Immediate social domain (Family)

The family is considered as one of the major stakeholders in many CBR projects. In any discussions on disability and rehabilitation, the importance of the family must be acknowledged. Disability not only affects an individual but also affects the whole family. The prevalence of disability in India ranges from 7% - 10% depending on various factors like definition and availability of information. Since the effect of disability is felt by the PWD and the family, it may be considered that almost 40% of people are affected by disability. In rehabilitation, the family is considered as a resource for the PWD. The aim of rehabilitation is to improve the quality of life of the individual PWD and the whole family. The WHO promoted CBR with the expectation of developing rehabilitation resources through trained family members (Helander et al., 1989). According to Dalal (2002, p.21), "Disability rehabilitation was primarily considered to be a responsibility of the family. Large and extended Indian families provided essential physical, emotional and economic support to its members with disabilities. Being cohesive and stable social units, families provided an identity and a sense of security to its members, irrespective of their physical disabilities."

In western countries, the needs of the carers of PWD are well recognized and hence there are special services offered to them like respite care. In developing countries with limited resources, attempts have been taken to address the problems of carers by encouraging the family members and persons with problems to form self-help supportive groups. The federation of haemophilia and a supportive group for people with acquired brain injury are examples of such groups functioning in some developing countries. In the Rehabilitation Institute where the researcher is working, there is a support group meeting once a month for the family members of people with acquired brain injury. The carers are exposed to the implications of ABI and different strategies in these meetings. This exposure enhances their understanding of the situations and improves their ability to cope with the implications of ABI.

In this study, interviews were held with the individual PWD and the immediate family (primary carer or a main contact person in the family). Within the interview, the role of the family in relation to disability and CBR intervention was explored. Under this subdomain, 11 emergent themes were identified:

- ✓ Characteristics of the family
- ✓ Dependency and severity of disability
- ✓ Adults with disability
- ✓ Gender bias as a PWD and as a carer
- ✓ Stigma and Discrimination
- ✓ Impact of disability
- ✓ Family support and participation
- ✓ Family's perception of CBR intervention
- ✓ Respect/Status
- ✓ Consanguinity and its importance in the local culture
- ✓ Domestic violence and alcoholism

5.3.1.1 Characteristics of the Family

The researcher has identified the following characteristics of in the families of PWD who were interviewed. Except for one PWD who lived in an extended family the rest were in nuclear families. Most of the family members were engaged in heavy manual labour in the market to meet the financial needs of their family. In most of the cases, both husband and wife were working and the young children were taken care of by elderly people if available, or by the older children in the family. Though the majority of the PWD came from nuclear families, support from extended families especially during crises was seen. The type of support differed with the age of the PWD, contributing role of the PWD and the nature of disability (temporary or permanent).

5.3.1.2 Dependency and severity of disability

Dependency in terms of activities of daily living, financial implications due to disability, support system in the family, etc were found to have direct associations with either disability and or with rehabilitation.

Children with disabilities were apparently dependent because of their age. In this study it was found that in the early stages, the family spent money and time on treatment/rehabilitation. When the expected improvement or cure did not happen, they got exhausted and started looking for alternatives for continuing care. There were three children (SK, KU, UM) who had multiple disabilities in this study. Of these children, two were sent to their grandparents for continuing care since the parents could not spare time for their care. SK was left with his father by his mother following a dispute. His father struggled to provide care during the day because of his work schedule. The same child was helped to join a residential home through VCBR. The other child (KU) had also been spending most of his time with his grandmother as the child could not be left alone at home when the father went out for work and mother was looking after KU's brother. UM's mother explain why she left UM with her grandmother. According to her,

> *"I used to keep her...I had to go out (for work)....no one at home to look after the child....we are living alone....no one around the child....that is why I have brought and left her with my mother here"*

She also mentioned an incident where UM's siblings assaulted/attacked UM when the parents were away at work, which resulted in bleeding on the face. This showed their inability to offer a secure environment for their daughter.

RA's grandmother took care of her because although her parents live next door, they were not supportive. Poverty seems to be the main reason for the lack of support. When the resources in the family are meagre, the non-disabled members of the family get the major share. In a joint family system, PWD and elderly persons are taken care of by other members. The joint family system is not common now and the nuclear family system with extended links and support of other family members is more common. This study showed that all

the children with disabilities received good support from the extended family (especially from the grand parents). In this study, children with disabilities were provided with continuing care mainly by grandmothers. This raised several questions: 'How long can an old grandmother support a child with disability?'; 'What will happen to the child when the grandmother dies?'; 'What about the needs and problems of grandmothers who are themselves experiencing disability due to age?'

What is the responsibility of the father or grandfather? Is it not gender bias? Does this imply there is a gender bias about who is a "carer". O'Toole and John (1991) analysed the relevance of the concept of parental involvement in CBR programmes in the context of Guyana a developing country. Twenty-four per cent of the Guyana sample represented single parents. The fathers' role in the other homes was minimal. The parents were asked about a number of housekeeping tasks within the home. Fifty-one per cent of the tasks were done by the mother alone; less than 1 per cent of the roles were performed by the father alone. The burden of the home is clearly on the mothers' shoulders; their ability to put aside specific periods of time to 'teach' the child would need to be considered carefully. Creative ways need to be investigated in which assisting the child's development becomes an integral part of the mother's day rather than making unrealistic extra demands on an already overburdened individual.

In VCBR, it was found that the LS's intervention in the area of activities of daily living and the grandmothers' active participation in LS training were significant. The LS for KU said,

> *"His mother carried out my instructions exactly. His grandmother too did the same"*

The LS for UM said,

> *"I have not given up...I have persisted...only the grandmother was there...she would bring whatever I asked for"*

However because of the severity of disability in these cases, the outcome of the interventions was not perceived as satisfactory by the team and the family.

In some cases it may not be possible to address the rehabilitation needs of a child with severe disability in the community. Some times even referral may not address the problem. In the case of SK, the concerned LS and other team members found it was not possible to address his needs in the community through VCBR, because of the severity of the disability and the lack of resources within the home. Following discussions with the family and the team, it was decided to institutionalize the child for care. Institutionalization/Institution based rehabilitation is usually seen to be against the principle of CBR. In this study, it was found that in situations of multiple resource constraints, institutionalization needs to be considered as an option within the CBR programme.

In summary, severity of the disability is found to affect the dependant nature of individual PWD. The wider family have to cope with the extra burden of their care. This role often falls on the grandmothers.

5.3.1.3 Adults with disability

The kind of support given by the family members to adults with disability included physical and financial support for medical care. People who live a hand-to-mouth existence do not have savings to fall back on in emergency situations. However, the family members mobilize funds usually by borrowing from moneylenders to manage acute problems. SU who met with an accident a long time back recalled the support rendered during the acute phase. He said,

"I am talking like this...because of the life (help) given by my brother"

Another person (DH) said,

"If he (son) did not pay, I wouldn't have survived"

In most cases immediate help and crisis intervention by family were present and seen in this study. However long-term support was not given in all cases.

5.3.1.4 Gender bias as a PWD & as a carer

In Indian families, in general, women are responsible for 'care giving' along with home making tasks. When they experience disability who will care for them? 'Can a male member take over the care giving role?'

In this study, women with disability experienced negative attitude and hesitation from family to provide care. Only one man with a disability (JE) had a bitter experience. The reason could be related to his pre morbid personality and his role in the family. Among the women, only one PWD had good support from the caregivers. Many women with disability (VM, VI, EL) felt hurt about the way they were cared for. VM said,

> *"she (daughter-in-law) will cover her face and hands while removing the bed pan because of the smell....she will cover the photo (picture of a God) with a cloth, so that he does not see what is unclean."*

In most cases women consider themselves responsible for the care of their male members if they become sick or a PWD.

Except for one person (VI), the carer was a female family member. In VI's case, her younger son was fully involved with her personal care during the initial phase when she was fully dependent for self-care. His care-giving role was not encouraged by other family members including VI. They wanted to replace him with a girl and the family did it by arranging a marriage for VI's elder son with the idea that the daughter-in-law would take care of VI. But the daughter-in-law was not prepared to offer help for VI and there was a conflict in this matter among the members for some time till the LS made VI partially independent in self-care. VI's son expressed his view that his sister-in-law did not attend to VI properly. The same person who did everything for his mother earlier now complained about his sister-in-law. The family's attitude reflects the strong gender biases and expectations of a daughter-in-law in this society. The son here does not seem to have a gender bias as he was the caregiver earlier – he only expected his sister-in-law to do what he had done.

This pattern of behaviour may be due to a strong cultural base, which acts against women's empowerment.

5.3.1.5 Stigma and Discrimination

Link & Phelan (2001) define stigma as the co-occurrence of its components – labeling, stereotyping, separation, status loss, and discrimination – and further indicate that for stigmatization to occur, power must be exercised.

In this study two individuals have described the family situations where stigma was evident which led to discrimination. VI was upset with her daughter-in-law for not allowing her to play with her grand child for a period of six months because of a fear of infection. This made VI very upset till her son got involved and shouted at his wife who finally allowed the child to play with VI. Scambler and Hopkins proposed two distinct forms of stigma: enacted stigma and felt stigma. Enacted stigma refers to episodes of discrimination against disabled people, solely on the grounds of social unacceptability, while felt stigma refers to the shame associated with having a disability and the fear of enacted stigma (Kassah, 1998). This kind of enacted stigma was seen only in VI's case.

Discrimination was reported in an interview with RA's grandmother and she complained about RA's parents' partiality to their other children. She angrily complained,

> *"you support the other girls to study; get them clothes; do good things for them; can't you do the same thing for this girl (RA)?"*

In summary, stigma and discrimination negatively affects the QOL of PWD and their families.

5.3.1.6 Impact of disability

In this study, female relatives pointed out the difficulties experienced when one of the family members became disabled. These included change of roles, extra work, and financial strain. HB's wife expressed her difficulties in running the family with increasing need and decreasing income caused by his accident.

> *"The day he fell down...since then more troubles.... taking care of children is more difficult...I cook for one day...I won't cook for two days...we are able to eat only one meal a day...somehow I am managing"*

In a few families, the difficulties and change were handled with some adaptation and adjustments. VN's wife spent less time in her business because she had to help VN's toileting. VN remarked,

> *"She used to feel tired after attending the business. .In that situation also, she used to take care of me without any hesitation."*

In this circumstance, VN had restricted his food and water in take so as to control the frequency of passing urine and bowel motions. VN's wife was aware of his management and advised him to take proper diet and she did not express her feeling of tiredness to him.

Management of problems due to disabling conditions depend on various factors. They may be duration of disability (short term or long term), temporary or permanent nature of disability, economic condition of the family, roles and responsibilities of family members.

5.3.1.7 Family support and participation

Most of the LS said that the family members were very cooperative when they gave exercises at home, with the exception of RA's parents. RA did not stand up for long period till the LS intervened. The LS approached RA's parents to set up a parallel bar for her to practice standing and walking.

The LS mentioned;

> *"I have spoken to her father and mother for setting up a wooden parallel bar...I tried to persuade her father to do this for a month. Finally he arranged for it after I told him that if he cannot do it I would organize others and do it myself"*

This is an example of how the family can be motivated by making them participate in the rehabilitation process.

In contrast to this there was an example of good support rendered by SU's mother to upgrade her hand sewing machine to a foot machine by borrowing money.

The above examples illustrate that good family support can enhance QOL of PWD.

5.3.1.8 Family's perception of CBR intervention

The intervention by VCBR helped to reduce the difficulties experienced in some families. For example, AR whose wife used to go rag picking, stopped, as AR was able to support her following intervention by the LS. In the case of SK, the admission of SK in a residential home had relieved his father from caring for him and he said,

> *"now I'm free sir.... without any problem ...I can do night duty...if there is a work, I will go for night duty...If he (SK) was there, I could not do night duty...now I am doing night duty...I come home at any time...I go out at any time"*

It showed that the intervention on the individual PWD enhanced the QOL of both the PWD and the family.

5.3.1.9 Respect/Status

There was an association seen between disability and the status/respect of the PWD in the family in this study. AR reported that his wife started quarrelling with him often since the income reduced following the disability" It was

observed during the interview with JE's wife that there was a change in respect/status given to JE by her. In contrast to this, DH said that there was no change in the respect/status but the family showed only sympathy (anuthabam). But for SU, the respect/status had improved in the family following completion of vocational training through the VCBR. This shows that there are a lot of factors responsible for giving a PWD respect by the other members of the family. The role and status of the PWD before acquiring a disability; capacity of other family members to substitute his/her role after disability; nature of disability (temporary or permanent); and severity of disability are some of the factors.

5.3.1.10 Consanguinity and its importance in the local culture

KU's parents were of the opinion that consanguineous marriage was the causative factor for KU's congenital disability. Both were convinced that others should not fall into the same trap. When there was a question raised by the researcher about KU's uncle's marriage, both the parents of KU said

> "*that they would advise the father not to arrange the marriage within the family circle. At the same time we will not compel our father because he is an elderly man and his dignity should not be affected.*"

In this case although there is no problem with knowledge the challenge is in the practice as there are issues related to culture and traditions of the community that hinder knowledge being translated into relevant practice.

5.3.1.11 Domestic violence and alcoholism

There was an association seen between conflict / violence in the family and alcoholism in this study. Four individuals reported conflicts arising as a result of alcoholism. In contrast only one PWD (VI) reported

> "*that her husband had never used foul language or physical violence in about 26 years of living together*" and she further mentioned "*he did not have any bad habits like consuming alcohol.*"

The story of VA is centred around the alcohol problem of her husband and the resulting domestic violence. When she became pregnant after a long time, he beat her under the influence of alcohol and she had an abortion. Since then she developed tremors and he stopped beating her following that incident but he did not stop consuming alcohol. When asked about the severity of the injury sustained, she replied

> *"No sir...but there was bleeding...eyes were swollen...head also swollen"* (the way she expressed was like as if she had mild injury)

The role of a woman in a slum family is really challenging, as she has to put up with alcoholism, poverty, work pressure and home making. The amount of stress and strain and pressure are enormous. When there is a PWD in the family, her role becomes even tougher.

5.3.2 Wider social domain (Neighbours and community)

Marx considers "man as a zoon politikon (political animal) that is not only a social animal, but an animal that can be individualized only within society" (Fuchs, 2003, p.38). It is the society, which moulds a person's personality. People need to interact with various social institutions, follow certain social norms and fulfil specific social roles in leading a good community life. In the course of social interaction, several barriers have to be negotiated. For a PWD to be in the midst of the social mainstream, additional barriers have to be overcome. Two-way communication and special preparation are essential for both the PWD and the wider community to maintain a harmonious relationship between them. A PWD has to prepare physically and mentally to re-enter the mainstream and society should be willing to accept PWD 'as he/she is' and provide a barrier free and disabled friendly environment.

In this study detailed interviews were held with individual PWD, their family members and the concerned LS on how social aspects influenced disability and rehabilitation for the individual. It was found that PWD had networks that included many individuals and institutions.

Emergent themes within wider social domain are

- ✓ Friends/peers
- ✓ Access and barriers
- ✓ Stigma, Discrimination, Inclusion in wider society
- ✓ Neighbourhood
- ✓ Community resources

5.3.2.1 Friends / Peers

Both positive and negative aspects were found when considering the role of friends in the life of PWD. In many cases, friends have offered timely help, financial support and participated in the rehabilitation. Some friends were reported to have a negative influence, encouraging consumption of alcohol or use other addictive substances. On the other hand many PWD reported that friends were a good resource for them, giving moral support and financial support.

5.3.2.2 Access and Barriers

Weddings, ear piercing ceremonies, house-warming ceremonies are some of the common family functions where relatives meet each other, renew their relationships and update themselves on family information. In this study, the disability affected participation in family functions. There were two sets of parents of children with multiple disabilities (KU & UM), who said that they could not fully participate in family functions. The children could not be taken, as it would inconvenience others. If they did go, they had to come back home on the same day to look after their children. Most of the time, only one of the parents could attend the function as other parent had to stay back to look after the child. KU's father said,

> *"If the function is held nearby...I go in the day...that too, either me or my wife will go"*

Adults with disabilities expressed the view that they did not like participating in family functions. There were two adults who were invited by relatives to attend

family functions and in fact one of them (VM) was offered the option of being carried by the relatives to the function. Both avoided the functions and when asked both said that they were not comfortable attending the functions because of their disability. Although friends and family did not appear to discriminate against PWD, social isolation still is a reality in the lives of PWD, preventing them from full participation in daily life. Disability and its associated psychological reactions like feeling low, poor self-esteem contribute to this social isolation. The stigma associated with disability could be another reason. This shows that time and effort has to be spent with individual PWD and the wider society, to prepare them for social reintegration.

5.3.2.3 Stigma, Discrimination, Inclusion in wider society

Inclusion and participation in social activities is indicative of acceptance as opposed to discrimination in society.

In this study there were two female PWD who expressed two contrasting experiences relating to attending festivals and pilgrimage. Although going on pilgrimage and attending festivals had spiritual connotations for the individual PWD, these also were opportunities for them to feel part of a community and to share experiences with others. KB's neighbour included her in a group that went by a truck to visit a 'Darga' (a holy place of the Muslim community) on a festival day. This trip gave her much happiness. In contrast, when asked about her participation in a local temple festival, RA said,

"what can I do...I am unable to go...why should I stop others from going"

The presence of an understanding friend or relative can help to remove barriers set up by stigma and discrimination. If PWD do not have such friends they continue to experience spiritual and social isolation.

CBR has scope to work with individual PWD and as well as with the wider community. Reactions to disability by society have to be considered while in a society stigma and discrimination may affect the way resources are allocated. Access to social resources by the PWD could be limited by the society's reaction to the disability. In this study, no one complained about society in

terms of his or her status or respect. One PWD (VI) commented about her status / respect in the community in comparison with her family said,

> *"I am not respected at home but at the same time, I am respected by the neighbours"*

Except for two individuals (HB & VA) out of 11 PWD who responded, the rest said that there was no teasing or ill treatment or any hurtful comments about their disability by the adults in the community. In fact many said that the people generally feel sympathy (pavam/irakkam) towards them. Only one individual (VI) had doubts saying that people might talk behind her back. However the reaction of the children towards disability and PWD was different from that of adults. Two children experienced negative comments, and teasing by their peers. The LS said about SK,

> *"He (SK) will crawl out of his house on all fours and the street children throw stones at him"*

In the case of AN, his peers started teasing him for wearing the spectacles which were prescribed for his headache and problem in seeing. This resulted in irregular use of the spectacles. His mother said,

> *"he was teased on the street...because he was teased, he did not use the spectacles regularly"*

UM's siblings physically abused UM while the parents were away.

The attitude towards PWD by non-disabled adults and children needs to be carefully looked into. In this study, it was found that some children showed negative attitudes towards PWD. All adults expressed their support and were sympathetic.

5.3.2.4 Neighbourhood

For PWD the immediate neighbourhood is the space in which most of their interactions take place. In this study, large volumes of information and powerful statements about the role of the neighbourhood in disability and rehabilitation were brought to light. In general it was found that the 'disabled friendly neighbours' were very resourceful. The neighbours in this study demonstrated a willingness to 'go the second mile'. The type of help given by the neighbours to the PWD ranged from the identification of PWD to rendering physical and

financial help to them. When the survey was undertaken in the community by the LS there were many instances where the neighbours helped to identify the PWD. This principle is utilized in Rapid Rural Appraisal methodologies (Kuruvilla & Joseph, 1999). The actions of the neighbours of KB & VI assured us that there are still good hearts and souls in the community and the CBR should work in partnership with these people. What had they done?

KB's neighbour said,

> *"no one in her (KB) house did anything...I'm telling the truth...only I was there to help her if she wanted to go anywhere...if her clothes were dirty...only I would help her to change it...If I am not there...my daughter does it"*

Similar help (mainly giving bath and dressing) was rendered to VI by one of the neighbours regularly for about three years. When asked about the reason for her help, she said,

> *"she (VI) is in this condition, so she needs help. It's okay if there were people to help, but in her house there are only men. She is a female like me...that is why I help her"*

VI's son remarked,

> *"If we (sons) could not go in time...they (neighbours) will give her food...even though we were not there"*

These are positive actions of support to PWD. It is usual to find discriminative and negative actions highlighted and published in the literature and other publications. This might discourage non-disabled people from participating in the rehabilitation process and encourage the PWD to develop antagonistic attitudes towards non-disabled people. Ultimately a society with two marked communities (disabled and non-disabled) will be added to the existing caste, and religion based groups.

5.3.2.5 Community Resources

There were many individuals and institutions in the community such as government functionaries, schoolteachers, local counsellors, moneylender, local police and the local priest who played their role in the rehabilitation of PWD either directly or indirectly. Some examples can be quoted. At the time of initial phase of VCBR, KU's mother approached the local pawnbroker to pawn her jewels in order to meet the hospital expenses for KU's treatment. The pawnbroker asked the reasons for pledging and immediately he guided the mother to the LS for further help. For AN, who is a student, the teacher played a significant role in identifying the problem and for addressing it. The teacher suspecting AN had difficulty seeing, identified AN's problem by seating him at various places in the classroom, in relation to the black board. Once convinced that AN had a problem with his sight, she had referred him to an eye camp. When his visual problem was confirmed by the screening test, she sent word to AN's parents to take him to the eye hospital for further investigation and intervention. The teacher found that the parents were careless and ignored the advice. She called the parents in for a discussion and advised them to look into his problem seriously. In the meantime, the LS got involved in organizing the check-up. A pair of spectacles was provided through VCBR. The teacher continued to monitor his condition and having understood his difficulties in handling the spectacles being a small boy, she took special care to help him. She said,

> *"He (AN) could see clearly but he found it difficult to handle the spectacles being a small boy. So I take care of spectacles by keeping them on my table. He may not be aware of their value. Whenever he has written work he can use them. Whenever he goes to play I collect and keep them on my table"*

This study had demonstrated a wide variety of resources within the community for VCBR. Some resources have been used effectively and some not. Neighbours were a resource that was often used. Arrangement for parallel bars for AR; assistance in exercise for RA; helping the LS in mobility training for VM, were some of the examples of how neighbours helped. KB's neighbour

followed up the LS involvement in getting an Identification Card from the Government for KB. She used this identification card to access social security benefit for KB. The resources of the schoolteacher and pawnbroker were not used directly in VCBR as the LS and the VCBR staff were not aware of them.

5.3.3 Summary of Social Domain

Disability affected the role, status, interactions and relationships of the PWD within their family as well as the wider social network, which in turn affected the QOL of PWD. Intervention by the LS included regular visits, use of local resources like neighbours and friends. This improved the interactions and relationships of PWD within the family and the wider community, which in turn led to a change in the role and status of the PWD. This led to improved QOL of PWD in the social domain.

Disability affected not only the PWD but also the whole family. Though many people live in nuclear families, support was provided from the extended family to the PWD as the need arose. The presence of a PWD in a family limited the social interactions of other members in the family. In addition, carers of children with disability whether parents or grandparents experienced increased stress because of the dependent status of the children.

In the VCBR coverage area, the role of women was found to be difficult. They had to put up with alcoholism, poverty, work pressure and home making. Women in a family either as a PWD or as a carer were 'doubly handicapped'. They experienced discrimination and stigmatization both as a PWD and as a carer. Many women with disability felt hurt by the way they were cared for; female relatives experienced difficulties such as change of roles, extra work and financial strain when one of the family members became disabled. The issue of gender bias in relation to disability needs to be studied further.

Intervention in some domains especially in the physical domain widened the social network of the PWD. A variety of people from the wider social network like friends, neighbours, priest, pawnbroker, and schoolteacher were supportive

to PWD. Friendly neighbours were found to be a helpful resource for improving the QOL of PWD. Institutions like school, church and government played their role either directly or indirectly for the improvement of QOL of PWD.

PWD did not experience stigma and discrimination from the wider community. However children did show negative attitude towards PWD especially to children with disabilities. This special group (non-disabled children) should be a focus for education in CBR. Awareness programmes, participation of non-disabled children in the network meeting of PWD would help in developing positive attitude towards PWD in the long run.

5.4 Psychological Domain

5.4.1 Introduction

Harmony of mind, body and spirit is crucial to keep a person in good health (Spector, 2002). Problems with body structures and functions not only affect an individual's physical health but also affect their thoughts, emotions and behaviour. Adaptation to physical disability is a journey through various psychological reactions by an individual. People with strange behaviour and difficulty in learning usually present with some behavioural and cognitive problems. The challenge for any CBR is to address the psychological problems of PWD as well as to protect the mental health of the wider community.

In this study psychological aspects of individual PWD were studied along with physical, social and spiritual factors. The psychological reactions for the disability were brought out through the interviews with individual PWD and their caregivers. This study did not include people with primary mental illness. The role of the LS in this respect and other team members of the VCBR were also discussed. Introspection, self-pity/feeling low/depression, anger, fear and memory, and intervention were the emergent themes from the psychological domain.

5.4.2 Introspection

Restricted mobility (either temporary or permanent) assisted some PWD to reflect about their past and future. There were both positive and negative thoughts reflected by them. Positive thoughts like setting goals for the future after recovery from a temporary disability and negative thoughts such as worrying about the future were expressed. While he was immobile for a short period VN thought about his previous behaviour, which had affected the family relationship. He further mentioned,

> *"Now I have to earn...I have to make the children study well with the earning...that is the primary plan...their life is our goal while we live".*

Some PWD expressed a mix of emotions including aversion, depression but also determination. For an example, VI who said,

> *"Some times while looking at the incidents at home...I wonder what I'm going to achieve by living; it is better to become sicker... I hate this (life)...But at other times I feel that I should live as before; I should prove that I can lead a normal life"*

It is said 'An idle mind is the devil's workshop' (an old English proverb). Sudden onset of disability and the resulting dependency status often makes a person feel depressed/worried/anxious. 'Why am I like this?' is the question asked by many. They do have meditative thoughts during this phase. This is the phase where a person who was physically active is forced into inactivity because of some illness/accident. One might use this period for retreating and to do a self-appraisal for planning the future. There is potential for positive outcomes if this phase is effectively used by the CBR team/volunteer. Listening to them, facilitating the process of sharing their inner feelings helps the PWD to come to terms with the disability. Once the PWD has come to accept the current situation, the CBR team/volunteer can encourage the PWD to do a self-appraisal and motivate them to plan for the future. In the case of DH, after discharge from the hospital, the LS motivated DH to restart his previous vocation and counselled his wife by listening to her; encouraging her; explaining her the impact of ABI. Another example of effective use of the

introspection phase is by VN following some improvement by exercises said that

> *"I certainly think that I can go for some business or some work; I have got the courage which I had previously. I have got the courage of going independently...that is why, I am thinking of going for some work."*

In summary, introspection could work positively or negatively in the context of disability.

5.4.3 Self-pity/Feeling low/Depression

Psychological distress following a disability is more common among persons who acquire a disability later in their life than people who are born with a disability or acquired a disability early in their childhood (Bishop, 2005). In this study, the researcher found that feelings of self-pity were common among PWD and their carers. Some reactions to the disability by PWD were

> *"I weep in the night"*-EL;
>
> *"better let me die"*-JE_L;
>
> *"I don't get sleep in the night; it (life) has become like this...I have become like this...I have become like a unclaimed dead body ...I weep in the night and I don't sleep in the night at all"*-VM

Many PWD and their relatives expressed their feeling of distress to the LS. One individual broke down during the interview by the researcher when he mentioned about the amputation of his lower limb. This shows the confidence of PWD on the LS and the VCBR team members and the rapport built by the LS with the family members of PWD. Suicidal thoughts were expressed by some PWD and there was a pattern among a group of PWD particularly among persons with ABI and stroke and their family members. Suicidal thoughts and anger were two common psychological reactions mentioned by this group (ABI & Stroke). The main carer of DH attempted once to commit suicide when she could not tolerate the behavioural problems of DH especially with the episodes of anger and his use of foul language. HB & VM both had suicidal thoughts expressed during interview. HB said

> *"often I get the idea of dying...I also think about my children"*

VM said

"I thought of buying rat poison or use the cannabis...I can leave this world without giving troubles to any one"

Depression can be prevented if the early symptoms are recognized in advance. Both PWD and their carers are prone to depression and they need to be supported in CBR. In the case of DH, having recognized the psychological stress of his spouse, the LS spent more time talking to her, listening to her and supported her while she was unable to cope with the reactions of DH. In the words of the LS

"I considered DH's wife as a patient who needed help in addition to DH...If not she would have committed suicide...I allowed her to share her distress...once she herself appreciated my support by saying that 'you are the reason for my patience'"

Special focus may be given to PWD who acquire disability later in their life. On many occasions, the PWD and their carers did not articulate their emotions openly. One of the challenges of CBR is early detection and prevention of depression among PWD and their carers.

5.4.4 Anger

Some of the elements like anger, problems with memory and fear were found to have a close association with specific types of disability: most commonly acquired brain injury (ABI) and stroke. For example, HB who had ABI said,

"I get angry for even small matters...even at home, when my wife is around, I take a knife"

Some individuals were aware of their own anger. HB highlighted that the main reason for the poor financial status of his family was his anger. In his words,

"no proper food now...no food for three times a day now...I'm suffering a lot...my anger is the reason for all these"

DH who also had ABI reported that he could not control his anger and once he damaged a cooking vessel in the home and quarrelled with his wife on several

occasions, VM who had a stroke reported that she used to get angry with her relatives and shouted at them several times and because of this has experienced non-cooperation from her relatives.

But both HB & VM said that anger was part of their personality since childhood i.e. even before acquiring the disability. The intervention through VCBR proved to have a positive impact on the control of anger for DH. He was referred to a 'supportive group for ABI' being conducted once a month for persons with ABI and their family members at the Rehabilitation Institute (one of the units under the tertiary care centre). He reported,

> *"...anger...I had anger when I came to Bagayam hospital (ABI support group)...having made several visits...no anger now"*

5.4.5 Fear & Memory

Fear and memory were also found to have a direct association with specific disabling conditions like ABI & stroke. There were two PWD (DH & SO) who mentioned about memory impairment and two PWD (DH & VM) mentioned they had become fearful of going out after accident. Repeated exposure and orientation helped them to overcome their problems.

5.4.6 Intervention

The role played by the LS in addressing the psychological problems of PWD in the community was evident in this study. Being there at the time of a crisis, listening to the problems, sensitiveness in understanding the stress, consoling, giving comfort, motivation, encouragement, reassurance and advice based on experience were different strategies adopted by the LS in VCBR. The experiences shared by the PWD, their family members and the LS supports the view that counselling and guidance skills should be part of a CBR training and intervention.

There were incidents of both direct and indirect intervention through the VCBR programme, which helped the PWD to cope with the stress. Many PWD had

acknowledged the help rendered by the LS in this aspect. Intervention on mobility had facilitated a PWD to come out from her 'low feeling'. In her words,

> *"I got an inferiority complex...that's why I could not do anything...I could not express my sadness to any one...Mary Amma (LS) came...and taught me exercises, which helped me to lift my hands and legs and I could come out of my house and visit my neighbour...this helped me to chat with neighbours...helped to express my feelings, reduce my burden and pass my time* - VI "

The same person expressed gratitude to the researcher at the completion of the interview for having given her an opportunity to express her emotions and feelings.

This clearly showed that there is a need for a 'listening person or a group' where the PWD can share their problems and express their feelings. Informal counselling done by the LS proved to be effective in addressing the problems related to psychological domain.

CBR should be sensitive in recognizing PWD and their relatives who are unable to express their stress/fear/anxiety directly or who are not aware of their own psychological problems. One of the LS made this remark about a PWD whom she helped through VCBR,

> *"she is a person who is unable to express the turmoil she is experiencing"*

Though in this study, people with mental illness were not included, the VCBR has helped many people with mental illness to get treatment in the secondary/tertiary care centres through the support of the LS. They were able to provide follow-up for people with mental illness whom they had referred for care.

In VCBR, birth and death information were collected during the monthly review meeting. Many deaths were reported to be due to suicide and this emphasized that "community mental health" efforts are needed for the wider community.

5.4.7 Summary of Psychological Domain

People with physical disabilities are at risk of developing emotional and psychological problems because of increased stress caused by the disability and dependency. Carers of PWD also experienced increased stress and emotional problems. Because of the dearth of mental health professionals to deal with the large burden of mental health in any community, community based initiatives like CBR address an important health lacuna.

In the process of coming to terms with disability, people experienced many psychological reactions such as feeling of self-pity, feeling low, depression, anxiety, anger and fear. A good understanding of these psychological problems and early recognition of symptoms of mental illness at the community level was possible through CBR. The Local Supervisors played a significant role in addressing the psychological problems of PWD and their carers through informal counselling and are therefore an important health resource for a community.

5.5 Spiritual Domain

5.5.1 Introduction

It is being recognised that traditions, religious practices, spiritual aspects of the community are facilitating factors in improving the quality of life of PWD. One cannot ignore the significance of these factors while planning for a CBR programme. Spirituality is a broad term and may be viewed as an umbrella concept under which one finds religion. Religiosity is an expression of one's spiritual perspective and refers to an external, formal system of beliefs, values, rules of conduct, and rituals. Raghavan et al (2002) found evidence for the support of religion (an expression of a person's spiritual perspective) as a primary means of coping with stress of illness and disability. In Sociology, religion is considered as a social institution. Spirituality may be seen as an individual element whereas religion may be seen as a community element. But

both are interrelated. Spirituality is a sensitive issue when dealt in a community setting. A better understanding of religious beliefs of PWD and their family members will facilitate the process of rehabilitation (Yamey & Greenwood, 2004).

In this study, the researcher was aware of the situation where there were possibilities for getting biased information as the researcher belonged to a Christian Medical Institution. During the interviews this area was carefully discussed without mentioning any particular religion.

Faith in God, prayer/worship, petition, visits to temples/churches/mosque (religious institutions), rites, celebration, devotion, awe, seeking for forgiveness, fate, custom, fasting/viradham (which is a spirituality related practice in which the person follows certain norms like ritual bathing, observing fast or food taboo and visiting the temple etc), dislike and thanking God were several issues that came up during interviews with individual PWD. The emergent themes for this domain are visits to religious institutions, worship, bargaining with God, seeking forgiveness, shifting of faith and belief and intervention.

5.5.2 Visits to religious institutions

Various elements of disability and spirituality were interwoven. Disability affected mobility, which in turn affected the ability of the individual PWD to visit the religious institutions for worship. There were practices mentioned about worshipping at home and also visiting to religious institutions. In general, people prefer to visit the religious institutions on auspicious days and on festival days. This was evident from many PWD and their family members in this study. (DH, SU, VA, VM, VI & KU's mother). SU who had polio but was mobile with a limp mentioned that she used to visit the temple every week. HB mentioned that visiting the mosque made him to feel less pain in his legs. KU's father expressed that visiting the church gave him comfort but in contrast UM's mother said,

"what is the point of visiting a temple when UM is in this condition".

KU and UM were children with multiple impairments and their condition was more or less same. But reaction to the disability by both children parents was different. In this study it was found that visits to religious institutions provided peace of mind for many individuals and also gave an opportunity for social reintegration.

5.5.3 Worship

In this study, some PWD felt (expressed) that their body (body image) has to be in a perfect condition, in order to worship in temple or for prayer at home. RA who was immobile due to her disability questioned,

> *"how can I go to temple with the crippled legs?"*

VI could not use both hands for praying to God (In Hindu religion, lifting both the hands and joining palms together while praying is the accepted practice) because of her impairment, and she angrily mentioned that

> *"why should I pray to God when the God put me in this condition, where I cannot bring my palms together to worship. I have given up and stopped praying"*

One individual stopped worshipping God, as she could not follow certain customs, which she used to follow before acquiring disability. The disability made her dependent on others to buy the pooja materials required for prayer, which she found difficult and so gave up doing pooja.

From this study it would appear that intervention in mobility and independence in a CBR will facilitate the PWD to carry out their spiritual practices. This is clearly evident from this study that physical outcome through VCBR encouraged the PWD in getting involved with spirituality. It has also been reported that increasing spirituality resulted in improved overall physical outcomes (Kaye & Raghavan, 2002). This was not seen in this study.

There were several methods of praying reported: for example at home, at temples/churches/mosques, praying daily, once a week, praying prior to some activity and before going to bed. Several spiritual activities were practiced to

get rid off difficult situations and to cope with stress and also to attain peace and happiness. To quote an example, KU's father mentioned that,

"I go to a Church and sit there and meditate for peace whenever I am not engaged in work".

VA who had multiple physical and social problems such as difficulty in carrying weights, living with an alcoholic husband and limited financial resources mentioned that

"I kneel down and pray the God with tears to get rid of my burden".

5.5.4 Bargaining with God

Bargaining with God for a change by an affected person or a family member of an affected person is a common practice in India. In this study there were three individuals who bargained for total recovery from their disabling conditions. JE had a plan to go for pilgrimage visits to Velankanni and Chetpet churches if the normal walking was regained. KU's parents prayed with a petition of supplying porridge in the temple if KU walked normally. UM's mother postponed tonsuring and piercing of the ear (a religious practice) for UM until she walked normally.

The above-mentioned cases clearly show that their expectation was total recovery from the disabling condition. In CBR, working towards fulfilling their expectation may not be possible all the time but at the same time, information regarding reality may be shared with PWD and their family members.

In contrast to the above-mentioned status (non acceptance of disability or bargaining with God for a change) there were evidences for accepting the disability as a fate and a condition given by the God.

5.5.5 Seeking forgiveness

In addition to this, seeking forgiveness was an important component of the individual's spirituality. Only one individual (HB) mentioned that he did not believe in the existence of God before the accident. After the accident he said,

"I thought there was no God now I have a fear that there is a God."

The same person reported that visiting a mosque relieved him of his pain.

5.5.6 Shifting of faith and belief

Some PWD had openly expressed their faith in God and some did not. Disability seems to have influenced the faith in God of some PWD. One individual (HB) said,

"I did not have faith before".

One of the individuals mentioned during the interview that they (family) pray to various Gods from two religions and showed the pictures to the researcher. But the same person was criticized by the wider community about this practice of praying to various Gods and was advised to have faith in only one religion while he was bedridden following an accident. It was observed that the wider community generally advise people who are in stress to shift their faith to another religion but their own family members did not like this. There were also instances of PWD shifting their belief and faith to other religion and one of the PWD and their family members reported that they felt comfort after the shift.

5.5.7 Intervention

"Viradham", the Practice of fasting is a commonly accepted way of praying to God in many religions. Three individuals reported about their practice of fasting. In one there was an association between the individual's alcohol problem and fasting. While on fast, VA's husband expressed that there was no problem at home as he was abstinent from alcohol, used to buy rice for the family and come back home on time.

In this study, there was only one instance mentioned about some spiritual advice given by a health professional for a PWD during the time of admission to the secondary care centre. The same person acknowledged the benefit of following the advice. Two individuals who had benefited from VCBR expressed their thankfulness to God for what they have received. KB who received the social security pension from Government through the intervention by the VCBR

had contributed the first pension amount for supplying food for the poor people in her area. VN who mentioned the LS's help for his mobility stated

> *"I thought that God sent a person to help; I thanked God for the timely help through her."*

This showed that how much importance was given to this area of spirituality, but this should be handled carefully as it is a sensitive issue.

5.5.8 Summary of Spiritual Domain

PWD reacted differently with respect to their faith in God. While some lost their faith in God, for others, the disability strengthened their faith. When PWD and their carers visited places of worship like temples, churches or mosques, some of them found it gave them some peace of mind and also encouraged social integration. Some of the PWD felt that their disability (imperfection of body) was a hindrance to worship.

"Bargaining" with God and converting was fairly common. Improvement in mobility and independence helped PWD to participate more fully in religious activities.

Persons facing disability and illness used various spirituality related activities to find purpose and meaning and a sense of hope for the future.

5.6 Economic Domain

5.6.1 Introduction

Health is wealth - a well known saying that can be applied to the life of a PWD. The impairment or disability sometimes affects the person's health status and this in turn affects the economic status of the individual/family. It is well known that the disability and poverty are interrelated and there are number of studies which seek to explain this (Albert et al., 2004; ILO et al., 2004; Yeo, 2001). Disability leads to poverty and poverty may be a cause of disability and

compound the problem of disability. This complex relationship between poverty and disability justifies the inclusion of economic developmental activities as part of comprehensive rehabilitation within CBR.

Source of income, expenditure pattern, financial burden, economic support, social security, debt trap and economic intervention were the emergent themes for this domain.

5.6.2 Source of income

Most of the PWD and their families are engaged in hard manual work in the unorganized sector. This work requires a good physique and stamina. As long as they are healthy, their income is sustained. The concept of saving for the future is not common in this group. In addition, existing government social security schemes are inadequate in their coverage and are difficult to access. Hence people are shattered when their health status is affected due to age, disability, or sickness.

In this study, a majority of the PWD and their families work as manual labour and their income ranges from Rs.30/- to Rs.60/- day. The survey conducted in the VCBR coverage area showed that 5509 (67%) people were adults and the rest were either children or aged people (33%). No information was collected about the unemployment status of the adults. It was observed that jobs for manual labourers are not available on a regular or permanent basis. They depend on the synchronization of the individual's health and the availability of jobs. Each household also has a large number of dependents, which is also an impoverishing factor. For example, AN's mother said that the income of AN's father from loading and unloading of gunny bags was approximately Rs.50/- per day but the income was insufficient as there are three children. There were two individuals who mentioned that their income was between Rs.70 to Rs.100/- and their sources of income were from a business (DH) and a regular job (HB). In some PWD, who had been living with a disability since childhood, there was no impact on the economic status. However disability acquired in later life seems to affect economic status. In some cases, there was a total loss

of income (AR, EL, DH, MU), in others reduction of income (HB) and for only one individual (SU) an increase. SU had an additional income through the compensation he received for the disability due to an accident prior to implementation of VCBR. The amount received by SU as compensation was very meagre (Rs.6000/-) after prolonged legal formalities and procedures. For HB, his previous employer used to give 50% of his salary after he acquired a disability.

Majority of people in VCBR work in the unorganized sector and they are paid on a daily basis depending on the availability of work.

5.6.3 Expenditure pattern

The practice of spending a part of their income in buying snacks between regular meals for children appear to be well established. Some of the men spent a portion of their income for their own pleasure like smoking and drinking alcohol. To quote an example, JE said,

> *"there will be a profit of Rs.50/- for every 10 litres of milk used. I need Rs.15/- to Rs.20/- daily for my beedi expenses."*

Alcoholism was one of the main reasons quoted for loss in wealth. AR's wife said,

> *"even after our marriage...he had two cycle rickshaws...he sold out...we lost everything because of his drinking habit"*

5.6.4 Financial burden

There was no difference in the expenditure pattern of PWD who had had a disability since childhood and those who acquired the disability later in life. There were three individuals (KU, RA & UM) who had been disabled from birth and for whose sake the parents had attended various places for treatment / rehabilitation. The financial burden the family had to bear caused a lot of stress, the family was often pushed to the stage of "giving up" because of poor outcome.

UM's mother used to visit the Children's hospital at Chennai from Arni while UM was with her parents. She explained,

> *"it was about one to one half years back....there was no change in her status....I took her to Chennai hospital...they asked me bring her daily for exercises....it was not possible for me to take her from Arni to Chennai every day by paying Rs.100/- a day...I took her for about 5 to 6 months...once a month...then we stopped going there"*

KU's parents went around 'doctor shopping' for treatment/rehabilitation for KU and spent a lot of money. The nature of KU's disability also required various kinds of intervention such as surgical correction of deformity in his limbs, long term training for parents, adaptive aids required to maintain posture and regular medicines to control fits. It was learnt that despite their limited economic resources they managed to contribute towards various interventions. For example, they contributed 50% of the cost of a special sitting chair, which was prescribed. KU's mother explained,

> *"We were told to buy a chair like a dining table where the toys can be kept and which he can take and play...it was like an exercise.... we were informed while we used to take him there.... we were asked to pay Rs.1500/-...we requested them that it won't be possible for us to pay as my husband was a cooly...then they reduced to Rs.750/-...then we paid Rs.750/- and brought this chair"*

This happened long before implementation of VCBR began in their area. If the VCBR was present, perhaps free treatment could have been given to the needy PWD. These experiences emphasize that the rehabilitation of a child with multiple disabilities requires a network of support from various levels including tertiary care intervention such as surgery. Cost seemed to be an issue for both the child's family and for the tertiary care centre. From the individual's point of view, there was a threshold/limit for spending towards some procedures, interventions or appliances. If the family is from a very poor background like KU's family, borrowing money at interest is the only option they have. Usually the family is willing to contribute to treatment/rehabilitation costs in the hope that there will be drastic changes following the costly intervention. When the

outcome is not perceived to be satisfactory they get fed up. In KU's case, because of financial stress, KU's father indicated that,

> *"it were better if he was dead...when there was no money and the tablets were finished"*

Many disabling conditions require life long medications, treatment and constant support from the family. The stress generated by the need for constant physical and psychological support is compounded by the economic demands made on the family because of the disability. These additional economic demands add to the sense of frustration, trouble and helplessness felt by poor families. In KU's case, his father was very concerned about KU's treatment but when the payment for it was beyond his capacity to pay, he felt helpless. After finishing the interview, KU's father requested the researcher for help in getting the medicines either free or at a concessional rate from the tertiary care centre. The researcher linked him with a programme at the tertiary care centre to get the medicines at a concessionary rate.

Situations of economic deprivation may lead to disabling conditions. Action taken to address the economic problems could prevent the disabling conditions. Therefore the scope of the CBR project has to move beyond the narrow definition of disability to include economic deprivation.

A case in point is that of 9-year-old Sujatha (name changed) whose family expressed their inability to spend money on lifelong medications for her. In her case, a lack of medication would lead to chronic disability is a case in point. By providing economic support through VCBR, she was able to maintain good health (See Box 5.1).

Box 5.1

Sujatha's story

Sujatha is 9 years old studying in Class IV in the nearby municipal school (Salavanpet, Vellore) She lives with her mother and a brother. Her father has another wife and is not supportive of them. Her mother is on daily wages, which she earns by plucking flowers. Additionally she does beedi work at home to support the family. Altogether she is able to earn around Rs.1000/- a month. The Child Health Unit of CMC diagnosed Sujatha as having a congenital adrenal hyperplasia of the salt – losing variety. In this condition, her adrenal glands fail to produce two hormones that are normally produced. These hormones are responsible for normal growth and resistance to illness. In the absence of these hormones, the body produces another hormone in excess, which can cause "man" like features in this girl and lead to abnormal sexual development. If the two hormones can be replaced as medication, the child will have normal development including normal sexual development. This requires her to be on regular lifelong medication, which cost Rs.500/- per month. Sujatha's medicines therefore require a half of her mother's monthly earnings. So far she managed because of subsidized treatment from the hospital. Since this was no longer possible this family faced double disability caused by economic deprivation and inability to pay for treatment, which could lead to further disability.

The impact of disability on the family's economic status was significant and largely dependent on the contributory capacity of the PWD in the family. Children with disabilities are in the dependent category of any family but when an adult becomes dependent because of disability the effect on the economy of the family and the burden to the carer become unbearable. HB's wife, who has been struggling to take care of the family since HB's accident said,

> *"since the day he fell down there are troubles...taking care of children...every thing is awful...I cook for one day...I won't cook for next two days...if we eat for one meal, we will starve for two meals"*

In real life, there are very few institutions, which offer comprehensive rehabilitation services, and they are mostly run by private organizations. The services offered by these institutions require payment and few institutions offer concession or free services to needy persons. In this scenario, institutions with expertise and advanced technology and with limited resources struggle to meet the needs of PWD who are from a poor economic background.

In VCBR, the challenge was to render appropriate help for persons with multiple disabilities like KU, including good referral services. There was evidence of irregular follow-up or discontinuation of an intervention because of financial constraints. AN who had difficulty in seeing was prescribed spectacles by the tertiary care centre but the parents did not take any steps to follow it up. The reason was explained by the LS,

> *"they told me that we could pay the registration and get medicines for Rs.100-Rs.150...but we could not buy the spectacles."*

Similarly DE did not go for second sitting for her bone setting due to lack of funds. RA's grandmother had attended the tertiary care centre regularly for about six months and then discontinued due to lack of funds to pay for the bus fare when RA was a child.. UM's mother discontinued attending the OPD in a Chennai hospital for the same reason. VI who had a stroke and was advised to monitor her blood pressure regularly had her check up done about one and half years back. The reason for this was explained by her,

> *"I feel giddy since I have hypertension...I could not go for a check up because no money for auto fare...it will cost Rs.20/- for going and Rs.20/- for coming back"*

Money is needed not only for the direct cost of medical care but also there are several indirect costs such as transport, food, charges for an attendant, and loss of the daily wage. In VCBR through the training of LS it was possible to address some of the access issues but not all. For example in the case of VI, the LS has made changes in her mobility and in self-care. But all access issues are not within the control of the LS. In the case of VI, regular monitoring of hypertension would involve either services provided at her doorstep or

transport provided to access medical care at the health centre. Issues related to access to medical care lie within the economic domain.

5.6.5 Economic support

The sudden onset of disability due to an accident, or an illness shatters a family in many ways. The family has to take immediate action for acute care. It was observed that the people in the VCBR coverage area do not have any savings to fall back on to meet unexpected expenses. In this study, only two individuals (JE and VM) mentioned their savings made they had good income in the past. None of the others mentioned savings at all. VN's wife justified the reason for not saving money - in her words,

> *"If we earn Rs.50/- per day, we spend that amount for the food...for buying milk for children.... we have not saved money...I do not have the idea of saving; we can save if we have enough"*

Less income and more expenses is certainly one of the reasons for not saving money. However the researcher observed that there are families who had the capacity, but did not save money due to their poor money management.

In this study, it was found that both secondary and tertiary care centres rendered financial support to some of the PWD. There was a group of PWD who had fractures following falls. All (DE, EL, JE, VM and VN) had gone to traditional bonesetters immediately after the accident. In all these cases, the PWD suffered complications such as pain, shortening of limbs, contracture and immobility after the treatment. In all of the above cases the LS were able to help them through their intervention. The researcher looked into the psychosocial and financial implications of seeking traditional bonesetters rather than attending a hospital for management of fracture. There might not be a major difference in terms of overall expenditure at the hospital and at the traditional bonesetters. Though in government hospitals the treatment is offered free, many people did not opt for it. They were not satisfied with the care given and there was the additional problem of bribery. At private hospitals, they were expected to pay a lump sum at the first visit itself. This is the bottleneck for

many who are unable to pay a huge amount at one time. But at the bone setting places, the payment could be made in instalments during each visit. This gives them time to mobilize funds between each visit. It came to light that financial support was often given by relatives and visitors in the form of gifts of money. For an example, VN's wife said,

> *"expenses have gone up for the bone setting (kattu); the expenses were high; since the people who visited gave some money, I did not feel the trouble; I have not borrowed money; I have not asked any one for financial help"*

This study showed that there is a good support system available for the PWD, which varies from individuals to institutions. In this study different persons like the milkman for DE, a priest for EL, a previous employer for HB, friends for JE, neighbours for KU and relatives for VN[19] whose willingness to give helped the PWD especially during the crisis. There was a special method of help demonstrated for KU by the neighbours.

KU's mother explained,

> *"we don't have jewels of our own...people whom we know...considering the condition of the child...they gave their jewels to me (for pledging) for providing care and told me that the jewels can be returned later"*[25]

Many individuals have been pawning their jewels for emergencies and there were instances where they lost their jewels because of inability to retrieve them from the pawnbrokers.

The experience of the researcher in addressing the problems of poor people for smooth completion of rehabilitation training at the Rehabilitation Institute (one of the units of tertiary care centre) is worth sharing (See Box 5.2).

Box 5.2

Stamp project

The Rehabilitation Institute is part of Christian Medical College, Vellore and houses a comprehensive in-patient rehabilitation programme for people with severe disabilities. There are about 80 people with severe disabilities at any point in time. Most of the PWD are people with spinal cord injury or acquired brain injury. One of our major problems is that many who need care are those who can least afford it. The prolonged in-patient stay that is necessary for effective rehabilitation therapy causes a loss of productivity that often overwhelms the hand-to-mouth economy of poorer patients. This was a challenge requiring new appropriate solutions. An opportunity to earn some income while in the institute would help to restore the balance, without robbing people of their dignity. This has led to the organisation of some income-generation schemes, like the stamp project. The stamps that Friends send from overseas, are cleaned, sorted and packed by such patients, and then marketed through cooperative marketing agencies. The money they earn in this way, is usually used by them for their day-to-day expenses through this period. This gave economic support to people with economic problems during the period of admission for rehabilitation, allowing the process of rehabilitation to be completed without difficulty.

5.6.6 Social Security

Other institutional support included social security benefits called old age pension for many individuals (EL, KB, SO, VI & VM), and financial support for setting up a shop for JE through VCBR. Among them only KB was helped to get the pension meant for PWD through VCBR and the rest had been receiving the pension earlier. The scheme for providing social security to elderly people who have no means of subsistence and have no relatives has been in operation in Tamil Nadu since 1962. In 1974, the government extended this to support PWD. Under these schemes, an amount of Rs. 400/- per month is disbursed to the beneficiaries, through Money Order, by the Special Tahsildars (Distress Relief Schemes) of Revenue Department. In addition to this a free mid day meal through the nutritious noon meal programme is given to the

pensioners. They are also given 4 kg of rice per month if the noon meal is not provided and 2 kg of rice for those who get noon meal. One saree per female pensioner and one dhoti per male pensioner are given twice a year during Pongal and Deepavali festivals. Those PWD who are aged 45 years and above whose permanent disability is 50 percent or more are also eligible for this pension. The scheme also relaxes the age limit if the hardship faced by PWD is severe. At the end of January 2005, 58,618 PWD were benefited under this scheme in Tamil Nadu (Tamilnadu Government, 2006).

Corruption is a part of daily life in India. There is a practice of deducting Rs.20/- from each person who receives the old age pension from government by the postman who makes the delivery. The beneficiaries of this scheme see this payment as a legitimate service fee and the majority do not have any complaints about this practice. However, this may be seen as an act violating the rights of the PWD.

5.6.7 Debt trap

The burden faced by families during a crisis and their management of finance require a critical analysis. Often the family borrows money at high interest rates to face the crisis and become *'permanent (payers of interest) debtors'*. Once they are caught in this *"debt trap"*, it is not easy to escape. The experience with RA showed this. RA who was immobile at the time of identification by the LS was made to stand up within a parallel bar following continuous efforts by the LS. But she required tertiary care intervention to further improve mobility. Considering the economic status of the family, the VCBR team offered her free rehabilitation intervention at the tertiary care centre. The VCBR team was shocked that they did not accept the free offer immediately. RA's grandmother explained,

> *"for building the house I borrowed Rs.1000/-...for attending funeral and related expenses it was Rs.1000/-...there was Rs.3000/- loan... how can the interest be paid? How can I go? I have already defaulted payment for three or four months"*

It is an example of how people are caught into debt repayment *"cyclone"*. The person could not take up the offer of free help because of the time lost – she needed this time to make money to repay debts incurred previously. This interview was held in March 2004 and about two years later RA was admitted at the Rehabilitation Institute for mobility training. RA's grandmother told the researcher at the Rehabilitation Institute that in May 2006 she received some money through the provident fund scheme following her voluntary retirement from beedi work, this helped her to pay back the loan and hence she could bring RA for admission.

There were five PWD who reported that they borrowed money mainly for acute problems, which ranged from Rs. 1000/- to Rs.50000/-. JE's wife who borrowed Rs.1000/- said,

> *"What to do? I had to run and get the loan. I have got debt for Rs.1000/-. I borrowed for weekly interest. I borrowed Rs.200/- from one person and Rs.300/- from another person. That is the problem (athan enakku manasu ithuva irukku). How I am going to repay?"*

DH's son had borrowed about Rs.50,000/- for DH's treatment.

5.6.8 Economic intervention

In this study, it was observed that there were interventions for improving the financial status of individual PWD through vocational training (SU) and help in availing of government benefits (KB). Many PWD (AN, AR, DE, DH, JE, KU, MU, RA, SO, UN, VA) were helped to complete their rehabilitation through free/concessional treatment under VCBR. This was perceived by the PWD as useful and timely support from VCBR. To quote an example, AN's mother said,

> *"If the spectacles were not bought through VCBR...there would have been problem for 6 months to one year...it would have made the condition worse and the amount to be spent would have been more"*

Physical rehabilitation aimed at making a PWD functional and independent frees family members from care giving and allows them to spend this time for other activities including economic activity. Economic rehabilitation of individual

PWD demonstrated that there is an improvement of quality of life of not only the individual but also the whole family. This study has shown the value of a good partnership with the government system to help poor people especially with medical care such as anti tuberculosis treatment through the DOTS scheme and free drugs for diabetes through government hospitals. But there was no evidence of government resources being used for any economic development activity in VCBR.

5.6.9 Summary of Economic Domain

In this study, the economic status of the PWD and their family members, their source of income, income level, expenditure patterns and its effect on their economic status were studied in detail. Their money management system, which included borrowing, the habit of saving, and management during a financial crisis, came to light in the study. In addition, the support system available for meeting financial needs including government support and the problems in accessing it were studied.

Most of the people in VCBR coverage area work in the unorganized sectors and are financially insecure. Their money management is poor and they do not have savings to fall back on in a crisis. People are willing to spend money as long as they have a hope of a total recovery/cure. Once they realize that a complete cure is not possible, they feel helpless and become troubled and upset. People borrow money at high interest especially for acute care management.

The family income of the majority of people in the VCBR coverage area ranges from Rs.30/- to Rs.60/- per day. Achieving the Millennium Development Goal of an income of a dollar (Rs.40/-) a day per person (equivalent to Rs.200/- for a family of 5) is unrealistic in VCBR coverage area.

In general, rehabilitation intervention was expensive especially in cases of severe or multiple disabilities. The presence of a PWD in a family created an economic problem that was a felt burden to many of the carers. Parents of

children with severe disability were particularly burdened due to the unending cost of care. Economic support was provided to the PWD and their families in many instances by their wider family, friends and neighbours.

The Government's social security schemes for PWD are potential sources of economic benefit for the PWD. The system however is subject to corruption. The interwoven nature of poverty and disability demands that CBR should be seen as a development issue as suggested in the joint position paper by ILO, UNESCO and WHO (ILO et al., 2004). Economic issues are complex and dealing with them requires working with a range of options from subsidy to vocational rehabilitation.

5.7 Vocational Domain

5.7.1 Introduction

In this study, children aged 5 years and above with disabilities, adults with disabilities who are either employed or unemployed, women with disabilities who are engaged in home making are considered in this domain. Vocation not only provides economic security but also enables self worth and identity as illustrated in Lakshmi's story (See Box 5.3).

Box 5.3 Lakshmi's story

The story of Lakshmi, which was published in a local rehabilitation newsletter called 'Rehab Murasu' supports the positive outcome of vocational rehabilitation. Lakshmi is a polio-afflicted girl hailing from a small village. The Social Worker of the department of PMR visited her village to recruit her for vocational training. During the visit, he was shocked to know how the villagers identified her. Lakshmi was identified as 'nondi ponnu' meaning a lame/crippled girl. She was enrolled in vocational training in tailoring. Having completed the vocational training in tailoring she started practicing the trade. Now the same villagers identify her as 'Tailor Lakshmi'.

Inclusion or exclusion, vocational options, home management as a vocation, impact on vocation and vocational intervention were the emergent themes under this vocational domain.

5.7.2 Inclusion or Exclusion

Among children who were involved in the study, only one boy (AN) was a student and the rest (KU, SK, UM) were idle because of their severe disabling conditions. Disability had a direct impact on the performance of students. Poor attendance and performance at school were reported by AN. But the teacher's sensitivity in recognizing the problem of AN resolved the problems of attendance and performance. This was discussed in detail under section (5.3.2.5).

5.7.3 Vocational options

This study gathered information on different vocational options available in the community, the impact of disability on vocational aspects of PWD and the vocational rehabilitation measures undertaken in VCBR. Vocation and its association with other domains like physical, psychological, economic and social were also explored.

Adults with disability were involved in a number of different vocations. They were engaged in manual labour (rag picking, rickshaw pulling, loading and unloading of heavy weights, digging the ground, working in agricultural fields); working for someone/some institution (beedi work, cook assistant, care of the sick, truck driver, money collector); skilled work (painting, weaving, candle making and leather work); and small scale business (street vending of fruits and eatables, tea stall, selling of brooms). Only one person (AR) said begging was his vocation. In addition, some women apart from working in the above-mentioned areas also had a significant role in home making.

Most of the jobs mentioned fall under the unorganized sector except for beedi work, which has some organized structures and functions. Almost all the jobs mentioned are irregular and seasonal. UM's mother said,

> *"not daily...only when there was rain we will get work in the agricultural field...there is no rain now...we are at home...if some one call us...we will go, otherwise we will be at home"*

Good physical fitness and endurance are required for most of the jobs usually done by the PWD. Shifting from one job to other due to physical and economic reasons was common among the PWD in the study. For example JE who was working in the bus stand loading and unloading vehicles had started a tea stall, as he found the hard work difficult. UN had shifted from flower work to beedi work as she developed pain in her neck and often became exhausted. But VA and VN shifted their jobs because of insufficient income. VA was engaged in candle and leather work and shifted to beedi work, whereas VN who had his own business, gave it up for paid employment and later shifted to riding a cycle rickshaw as the income from previous jobs was not satisfactory.

5.7.4 Home Management as a vocation

Women with disability or caring for a child with disability are doubly disadvantaged. In general, the home management role is not recognized as a vocation as there is no monetary income. Regardless home management should be considered as a vocation as women take the major role in home making. If women do not carry out home management, either due to their own disability or if there is a PWD who needs her care in the home, someone else has to take her role. This is likely to affect the income of the person who undertakes the role. KU's mother has listed her daily tasks, which included sweeping outdoors, washing vessels, feeding KU, giving medicines to KU, cooking lunch, feeding again in the afternoon, making KU sleep, sweeping the floor, making KU sit in the special chair, washing clothes, fetching water etc. If calculated in terms of money for the tasks carried out, house management especially with a PWD at home should be considered as more than a

'vocation'. No wonder these mothers became easily stressed! Special attention should be paid to the mothers of PWD any CBR programme.

In VCBR, while recruiting volunteers to act as LS, a preference was given to family members who had a PWD in their home. No one came forward to act as volunteers from such families. The daily routine of KU's mother makes it clear why there was no representation from the families. There were two PWD who had mentioned that they were involved in home making to some extent after acquiring their disability. The VCBR, however, has not addressed specific issues related to home making. Home making is a challenging role being performed by women and which does not allow them to take leave or rest, unlike a job where a person can take time off from normal duties. The amount of work being carried by poor Indian women for day-to-day living is enormous. For example, in the slum areas where VCBR is in operation, during summer the water supply is irregular. Some of the regular routine work of the home such as washing clothes cannot be done till the municipality supplies water. When this happens there is a flurry of activity so that the washing can be completed while water is available. In addition, collection and storage of water adds to the work of the already overworked housewife. In this kind of life, it is almost impossible to find time for rest or leisure.

5.7.5 Impact on Vocation

Disability had a direct impact on various aspects of vocation. Poor performance and reduced work output, difficulty in carrying out task, shifting to an alternate job, and loss of job were all reported by PWD. DE who was doing beedi work could not work for a period of two years when she had a bandage/splint supplied by the traditional bonesetter. VN who was active till he met with an accident said,

> *"Lot of impact on the work because of the injury sir... I am not doing the work...I am idle at home...I do not feel strong enough to work"*[12].

VA stopped doing beedi work because of her tremors[9]. One individual was about to discontinue doing beedi work because of her difficulty in seeing.

In some cases the disability of children affected the work of their mothers. KU's mother stopped her agricultural cooly work, as she had to take care of KU[11]. But UM's mother in a similar situation continued her agricultural cooly work and instead left UM with her grandmother. As discussed earlier, the amount of work within the home, which is varied and unpredictable places a large amount of stress on women who are homemakers. In addition if they have to be involved in income generation, the stress experienced by them is even greater. If they cannot go to work because of the need to care for a child with a disability, the income of the family drops significantly. In families where income is already limited the increased expenses for the child with a disability and the loss of income when the carer stops working may be resented. This may lead to discrimination against the child in the family. It is a challenge for any CBR programme to provide proper care for a child with disability and to sustain the income level of the child's family.

5.7.6 Vocational intervention

Two individuals (DH & HB) were offered alternative jobs by their previous employers at half the salary that they had earned before acquiring the disability. HB discontinued his work after a short time. At the time of his injury, the VCBR was not in operation and DH was not willing to go to work out of fear. At this time the LS encouraged him to join the head injury support group. The motivation and support he received in this group enabled him to overcome his fear and take up the offer of work. Perhaps if HB had been in a support group he too would still be working. Because DH participated in the support group at the tertiary care centre other services such as counselling by the psychologist were also available. These interventions along with the encouragement by the LS and his wife were probably responsible for his continuing to go to work. When the LS first found HB, it was four years after his injury. Although advice to participate support group was given to him as to DH, HB did not make use of this facility. It is possible that if our intervention had been soon after the injury his response may have been different. This points to the importance of early identification and intervention through CBR.

Vocational guidance and vocational training were two major services related to vocational rehabilitation in VCBR. It involved advice, encouragement, motivation given by the LS, counselling by the team members at the tertiary care centre, and referrals to the vocational training centre. It was reported that the LS had motivated many PWD (HB, MU, SO, SU & VA) to learn a vocation from a training centre or start a small-scale business. In practice only one individual (SU) availed of the opportunity for vocational training.

The way they (LS) expressed the significance of a vocation to the PWD was very impressive. To quote an example of how VA was advised by the LS,

> *"if you pedal the sewing machine, it will be like an exercise and your time will be passed... you can also earn some amount...it might relieve you from the family burden due to your husband's alcohol problem"*

But VA did not join the vocational training and the reason mentioned by her was that her husband was suspicious and objected to her going out of house. The LS emphasised several factors like physical benefits, leisure and economy as advantages of a vocation. But for VA, the social situation acted as an inhibiting factor.

The LS motivated SU for vocational training in tailoring. During the follow-up by the LS after SU started practicing her vocation, the LS learnt that SU needed support. Although the LS offered to help by developing marketing support, she was not interested in taking her tailoring beyond a basic level. Research in the PMR department, CMC demonstrated that regular follow-up and continuing intervention is essential if the gains of a vocational training are to be sustained over a period of time (Guru Nagarajan et al., 1995).

This study also highlighted the influence of other domains like the physical and psychological domains on vocation for many PWD (AR, DE, DH, EL). AR was bedridden till the LS facilitated intervention at various levels (community, secondary and government). Improved mobility helped him to work. The interaction with the team and the repeated visits of LS improved his confidence.

DE said that the exercises, which she learnt through the LS, helped her to restart her beedi work. There were two individuals who claimed that the intervention on mobility (EL) and psychological support (DH) helped them to get back to their previous work. But both mentioned that they were paid less than before. EL who is a street vendor claimed that she could not procure more items for sale due to her limited mobility and this was the reason for her reduced income. For DH, his employer was sympathetic and considering his disability his status and offered a job in the market where he had worked earlier. At the time of interview, DH was not physically fit enough to do the hard work. His contribution in the market was less compared to his pre-morbid status and this was the main reason for reduced income.

Another method of intervention by the VCBR was through financial support, as for example that given to JE. Having analysed his circumstances, Rs.500/- was arranged through a local church to restart his tea stall. This amount was sanctioned mainly to retrieve the tea stall utensils that were pledged and to invest in restarting the shop. He restarted but after a short time he closed the shop again. As he had pain in his limbs, other family members got involved in the management of the shop. This resulted in a mismanagement of finances and led to him closing the shop. He now runs the tea stall himself. The researcher had an opportunity to learn a lesson from his story that "no one can brand/comment/label any intervention as a failure at any point in time; there are lots of opportunities for the failure to become successful".

This study has brought out various direct and indirect interventions in the vocational domains of many PWD, which have resulted in positive outcomes. Empowerment of PWD through the vocational rehabilitation has been demonstrated.

In VCBR, direct intervention in the vocational domain was done through referrals to the tertiary care centre for vocational training. There was no attempt to offer vocational training in the community itself. It was also observed that the vocational needs of women with disability or having a PWD at home were not recognized by VCBR. Home making skill training was not part of the VCBR.

Neither was there evidence of coordinated effort with the government for vocational rehabilitation or use of self employment loans or vocational training given by the government. There appear to be difficulty in getting access to the government loan schemes, as there is a reluctance/fear on the part of the VCBR about the formalities and problems of corruption in accessing such government schemes.

5.7.7 Summary of Vocational Domain

Aspects relating to the education of children with disability and vocation of adults with disability were considered under this domain.

The government has promoted inclusive and integrated education for children with disabilities. In practice, it was found that children with severe/multiple disabilities did not benefit from these schemes. Special educational/ rehabilitation strategies are needed for such children. Teachers were a resource in VCBR especially for identification and follow-up of children with disability.

In VCBR coverage area, most people work in the unorganized sector where there is no job security or regular income. Most jobs require good physical fitness and endurance. Disability affected the vocational domain of many PWD. PWD in this area had difficulty in finding an alternative and suitable employment. In some cases, improvement in physical, psychological and economic domains helped PWD to find alternate employment. For others vocational guidance/counselling and vocational training were given but only one person made use of the training.

In some cases parents of the children with disabilities could not continue with their usual employment because of the burden of care required by their children. Group initiatives could provide support and free time to continue the usual employment. Making it possible for women with disabilities to carry out homemaking activities independently was not given any importance but this is an essential area for vocational rehabilitation.

5.8 Leisure

5.8.1 Introduction

Leisure has been considered as one of the domains of quality of life of an individual. Leisure is a well-established concept in many developed countries but in developing countries, for those living a hand-to-mouth existence, this concept is not familiar or common. Nevertheless government and non-government organizations in developing countries do mention leisure and recreation when discussing the rights of children especially children with disabilities. Leisure and recreation were stated in the priority list while framing the national policy for protecting the rights of children in South Africa (Lansdown, 2002). One cannot underestimate the value of the leisure in one's life. It not only gives pleasure and satisfaction, but also sometimes gives one an identity in the community. PWD need recognition in the community and the pursuit of a leisure activity may facilitate this. Bishop (2005, p.4) suggests that "the rehabilitation counselors should explore the client's experience in the domains of mental health, physical health, family relations, social relations, relationship with partner or spouse, economic situation, leisure activity, and the religious or spiritual domain."

5.8.2 Common leisure activities

The researcher found that there was lack of awareness of the concept of leisure and hence it was difficult to collect information about this domain. There were two female PWD, who said that their routine work was their leisure. On continuous probing, a list of leisure activities were reported; these included watching TV, movie, craftwork, reading books, playing with children and some games like football, kabadi & goli (a game with marbles).

Watching TV was a common leisure activity being practiced before and after acquiring disability. Other activities were practiced only before acquiring disability. Restricted mobility, status of dependence and difficulty in seeing were some of the reasons stated for not undertaking leisure activities. To quote

an example, JE who was very proud of his walking up to 32 kms to see a movie before he acquired a disability now said

"I can't go...I'm bedridden...I lie down in the shop...I go for a walk and return back"

Although the VCBR activities did not focus on leisure, the network meetings provided a space for PWD to meet, sing and play together. Through this the PWD were encouraged to express their talents and also to feel refreshed, relaxed and diverted from their routine.

In VCBR, the LS have been trained to co-ordinate leisure activities in their areas. One of the LS encouraged the local children to participate in PWD network meetings. They were able to introduce many games in the network meetings. This strategy not only helped the VCBR to explore different common leisure activities but also encouraged a wider community involvement. In an attempt to screen the problems of old people in one of the VCBR coverage areas, the LS and the VCBR staff conducted ice-breaking games and many participants said,

"by playing these games, we feel younger".

5.8.3 Summary of Leisure Domain

The concept of leisure though well recognized in developing countries, was not a concern in the VCBR coverage area. But where it was present, watching television, playing games were mentioned commonly as leisure activities before acquiring disability. PWD did not perceive an inability to pursue these activities as a loss. It is a challenge for the CBR programme to identify culturally appropriate leisure activities, which should be cost effective, easy to learn and disabled friendly.

5.9 Lifestyle

5.9.1 Introduction

Lifestyle includes patterns of social relations, consumption, entertainment, dress and way of living. A lifestyle typically also reflects an individual's attitudes, values or worldview. Life style in this study was interpreted as behaviours and practices, which affect/influence a person's health in either a positive or negative way.

5.9.2 Common lifestyle issues

In this study the reported issues which reflected on lifestyle tended to have a negative impact on health. These were smoking, alcoholism, substance abuse, gambling and extra marital relationships, of these, smoking and alcoholism were very common. None of the women with disability discussed the above lifestyle related issues (culturally women do not smoke). However some of the women were indirectly influenced by these issues, because men in their family were affected. The researcher came to understand through discussions with LS that some women have also been involved in drinking alcohol and extra marital relationships.

Peer influence and pressure were the reasons for some PWD's problems with alcoholism and smoking. In addition to these, the influence of the social environment was seen. VA's story was centred on the alcohol problem of her husband and an example of how the social environment was associated with their problem. VA's husband had worked in an arrack (locally made alcohol) shop while he was a very small boy and his wife had run a refreshment stall to cater to the consumers of illicit arrack, which was sold commonly in their residential area.

Some individuals had attempted to get rid off the habit of drinking alcohol by approaching medical institutions (JE) and also by abstinence from drinking alcohol through spiritual/religious means (VA).

For some individuals, their habits of drinking alcohol and smoking were part and parcel of their life. AR proudly said,

"beedi is my food (rice)".

This had impacted on the individual's physical health, financial status, family harmony, and status in the community.

AR's wife said,

"Whatever he earned he lost it by drinking and also he had sold all the belongings for drinking".

JE said,

"My wife started fighting with me.... I take jewels for borrowing money without the knowledge of family members..."

Of the 20 PWD studied, accidents were the main cause of their disability (8 PWD). Of these eight, 5 met with accidents when they were under the influence of alcohol. There were two individuals (SK & VA) whose disability was due to birth and degenerative reasons respectively. Although the cause was not related to alcohol, some of the members of the family had the habit of drinking alcohol, which indirectly affected the quality of life of SK and VA.

In some cases, the disability had influenced their habit of alcohol consumption. Following a traumatic brain injury, DH who used to drink alcohol regularly prior to his accident developed an aversion towards alcohol and smoking. His family is very happy now. In the case of JE, he stopped taking alcohol because of ill health and restricted mobility after his accident but his wife is not confident about this status because she feels that he could resume his habit at any time. HB's wife said that he abstained from alcohol as long as he was immobile. Once his mobility started improving, his friends encouraged him to drink alcohol and smoke ganja (canabis). This showed the interwoven nature of lifestyle issues, the social environment and disability.

The evidence presented in the previous section on Wider Social Domain reflected on the helpful nature of people in the community where VCBR is in operation and are pertinent to positive lifestyle.

5.9.3 Intervention

There were several occasions, when the LS and the VCBR staff attempted to intervene in the problem of alcoholism but there was no cooperation from the PWD. In the case of VA, the LS and the VCBR staff attempted to address the problem of alcohol addiction in VA's husband. But he was not interested in giving up his habit. The intervention by the LS for the improvement of health status of the individuals indirectly influenced certain lifestyle issues. AR's wife said,

> *"Because of Maryamma, his health was improved...he is free from alcohol now ...why should I tell lie....but for Maryamma, he would not have survived".*

This emphasizes the scope of CBR including sensitization of the wider community on various aspects of lifestyle issues along with intervention for individuals. Topics like the ill effects of alcohol and smoking were included in the school awareness sessions and in health exhibitions under VCBR.

5.9.4 Summary of Lifestyle Domain

Whilst the interviews reflected both positive and negative lifestyles smoking and alcoholism were common.. Both were a part and parcel of people's life. Alcoholism was one of the major reasons for accidents and resulting disability. Peer influence/pressure and the social environment were the reasons for the high prevalence of alcoholism and smoking. Because of restricted mobility and limited social contact due to disability, the consumption of alcohol among PWD was less.

5.10 Summary

This study has highlighted the multidimensional nature of quality of life. Disability affected the quality of life in many different ways. Physical, psychological, social (immediate and wider), economic, vocational, leisure and lifestyle were the different domains analysed. The study found that different

domains of QOL were interrelated and improvement in one domain as a result of rehabilitation led to improvement in other domains and resulted in improvement in QOL. For example, intervention for improvement in mobility proved to have a profound effect not only on mobility but also on other domains like social reintegration and the psychological and vocational domains.

Disability not only affected the individual but the whole family. The QOL of women in a family as a PWD or as a carer, parents/grandparents of children with severe disabilities were found to be most affected. Support given to PWD especially during a crisis by the extended family contributed to the improved QOL of PWD. In addition to this many individuals and institutions from a social network played a role in the improvement of QOL of PWD. Among them neighbours were found to be very resourceful.

PWD did not experience stigma and discrimination from the wider community. However children did show a negative attitude towards PWD especially to children with disabilities. Initiatives like school awareness programmes and setting up of fora like 'Friends of PWD' could help in developing positive attitude towards PWD in the long run.

The mental health of people in any poor community is often not a priority. People with physical disabilities have an increased risk of developing mental illness. In VCBR it was possible to address the mental health needs of PWD through the LS.

The spiritual domain of PWD and their carers affects their QOL and should not be ignored but should be handled carefully and with tact.

Disability compounds an already poor economic situation for most people in VCBR coverage area. Loss of vocation, lack of savings and increased expenditure for care all worsen the economic situations of PWD and their families. Economic support from wider social networks helped many PWD to cope with the acute crisis. The long-term economic burden was dealt with

through a variety of measures like free appliances, subsidized treatment, vocational training and social security benefits.

Education of children and employment of adults were affected by disability. In VCBR, the nature and severity of disability, lack of education and alternative employment opportunities made rehabilitation difficult and challenging. Innovative approaches for alternative education, employment and vocational training are needed to address this problem.

Lifestyle can cause disability as well as influencing rehabilitation. In VCBR alcoholism was one of the major reasons for accidents and resultant disability. Lifestyle related issues like alcoholism and smoking should find a place in CBR as a part of disability prevention.

CHAPTER 6 FINDINGS

ROLE OF SECONDARY AND TERTIARY CARE IN CBR

6.1 Introduction

This chapter explores how in VCBR the role of secondary and tertiary care services/centres have influenced the QOL of PWD. As in the previous chapter, a proposition was used as a template for this exploration. The proposition is that "The quality of life of PWD in the community can be improved by linking community based services to secondary and tertiary care services".

Problems associated with disability are multidimensional and interrelated. These were demonstrated / discussed in chapter on 'QOL domains of PWD'. In any community, the severity of disability varies from mild to severe among PWD. It has been demonstrated earlier that people with mild disabilities can be rehabilitated in the community itself through the trained LS. People with moderate disability might need some intervention at the secondary/tertiary care centres for a short period of time but most of their problems can be addressed in the community itself. But people with severe disability might need intervention at a secondary/tertiary care centre for a longer period of time and also need regular check-up/review at these centres in parallel with community support. In a CBR project, the role of the LS depends mainly on the needs and problems of PWD and hence her role will change based on the need. At the community level, the previous chapter has shown how the LS played different roles like training the PWD and the family, helping the PWD to utilize the resources and sensitizing the wider community about the problems, needs and abilities of PWD. Another important role, the LS had in VCBR was to refer PWD whose needs and problems could not be addressed at the community level to the appropriate centres.

The researcher has explored the value of secondary and tertiary care services for the PWD in a community based rehabilitation programme for improving their quality of life. In VCBR, the Low Cost Effective Care Unit (LCECU) acted as a secondary care centre and the Christian Medical College Hospital including various departments like PMR, Ophthalmology, ENT and Psychiatry acted as a tertiary care centre. In this study the information shared by the PWD, their family members, concerned LS through interviews and also the information from various documents like review meeting minutes and monthly meeting minutes were collated.

This chapter is presented under the following themes: Referral system, empowerment, feedback, follow-up, interaction between community, secondary and tertiary care, learning from people and reaching the unreached.

6.2 Referral system

VCBR has established a referral system to link the community, the secondary and tertiary care centres with one another. This referral system was for the benefit of the PWD as well as the rest of the community. It was suggested that the LS can refer any person with illness to LCECU directly. In the case of a person who is not in a position to pay the fee, concessional treatment was made available. It was emphasized that the priority should always be given to PWD, not the general community. A training session for the LS regarding the details of referrals, including their role in follow-up after referral was conducted. The guidelines for referral were framed, and referred to regularly. The responsibility of the LS for the follow-up of those referred was discussed. Fieldwork information from the LS/individuals in the community and users was sought as part of the ongoing evaluation of this venture. The rates of attendance of PWD at the secondary/tertiary care centre and their health status after discharge were analysed.

Of the 20 PWD included in the study, 13 PWD had some intervention either at secondary or tertiary care centres or both. However, they all needed care and

intervention at the community through LS. There was a group of PWD who had 'difficulty in seeing' who required the LS's support for identification, referral and follow-up. The role of secondary/tertiary care centre for addressing the problems of persons with difficulty seeing was straightforward and the LS's role was limited when compared with other disabling conditions. Most of the cases who presented with difficulty seeing were those with cataract problems who needed surgical intervention. The LS's role for these people was identification, referral to the eye screening camps conducted by one of the tertiary care centres (Ophthalmology department), and follow-up after surgery/IOL implantation. The LS had the privilege of recommending those who could not afford treatment for free or concessionary care in the Ophthalmology department through the VCBR. This practice of referral to an existing facility is an example of sustainable care, which will continue following the closure of VCBR. There were also referrals to other institutions by the LS depending on the needs of PWD. For example, SK was referred to a residential home as his problems could not be addressed in the community. He was referred to a residential home to ensure a safe and good quality of life.

For some PWD, the LS referred them to secondary/tertiary care centres for a variety of reasons, including health related reasons, which were not always associated with disability. In this way problems or barriers faced while intervening at the community level and multiple problems due to the severity of the disability were addressed. The success of any referral system depends on the commitment of all concerned to ensure smooth flow of information and patient care between primary, secondary and tertiary parts of the system.

6.2.1 Empowerment through the referral system

In this project over the course of time, increasing numbers of non-disabled persons with general health problems have made use of the referral system. The referral system has played a role in empowering the LS in the community to do their voluntary work. All the LS were given the right to recommend deserving persons for free/concessional care at the secondary/tertiary care centre. This has improved their status in the community. One of the LS said,

"They have given referral ...it is like a letter pad...we can help very poor people" (She was referring to the printed referral slips that the project had given her.)

A person with infected ulcers on the feet due to diabetes from the VCBR coverage area was afraid and uncomfortable about attending the LCECU as he had discharged himself against medical advice earlier for some other problem. His wife approached the concerned LS and sought help for her husband. In her own words,

"Then I went there...I told my husband long back...he did not listen...what can I do...please help me...give a slip...my husband is suffering from pain in the leg and crying...she gave me a chit"

This has restored the relationship between the patient and the LCECU and enabled the patient to receive good care.

The community has come to consider the LS as a representative from the LCECU. The LS felt that they are like a bridge between the community and the LCECU. While discussing what would happen at the closure of VCBR and what would be the role of LS after the closure, they requested the LCECU to continue to accept their referrals. This shows that the referral services have been perceived to be useful by the LS.

6.2.2 Feedback through the referral system

Some PWD were referred directly by the LS to the tertiary care centre for vocational training; or to the support group for persons with acquired brain injury; or through secondary care centres for investigations or for surgery.

Those who were referred to the tertiary care centre reported varied experiences at the centre. VA's husband who accompanied VA for an investigation at CMC said,

"I was happy. Do you know why? There were people who paid for their investigation waiting...I was penniless, but I was called first. I am happy about it."

MU had a different experience when he was referred to CMC for amputation and he said,

> "That doctor came and asked *'Where is the blood?' Only one person has given blood...what about the other three persons?"* My wife said, *'Our people have gone to mobilize blood donors...they will come in the morning'.* He said *'It won't be possible'* and pushed my wife and said *'He will be discharged tomorrow"*

These experiences (feedback) may be shared with secondary and tertiary care centres to improve the quality of service and reduce such barriers to care.

Another PWD (JE) who had a fall and presented with a fractured femur was referred to a health screening camp by the concerned LS. The reason for referral was that despite mobility restriction, he had fever, tiredness and was very sick. At the camp, he was found to have high blood pressure and high blood sugar. He was immediately referred to the LCECU for treatment. JE was happy about the timely intervention for his health problems as well as for his mobility. He said,

> *"There was no change (sugam) after the puthur kattu and from Sathuvachari and also from Kattupadi. After that I came into hospital, because of my difficulty in walking. Peria Dr. Amma gave me a chappal with some height correction and stick. With that and also with my courage I walked."*

The same person who fell sick again at a later stage and was brought immediately and his wife commented,

> *"We have brought him now.. That day when there was rain ...He became sick (different)....We rushed here and registered and got treatment. Otherwise, he would have been dead."*

6.2.3 Follow-up

Speciality centres/tertiary care centres invest a lot in rehabilitation intervention, but are seldom able to monitor and regularly follow-up after discharge. Though after rehabilitation training, the PWD would be advised to come back to the

tertiary care centre for review/check-up, only a few PWD are able to follow this advice for a variety of reasons such as lack of funds, poor transport, and non availability of persons to accompany the PWD. In developed countries, the community rehabilitation services are well established and the PWD are referred by the tertiary care centre to these community rehabilitation services. In India, the referral system functions from 'bottom-up' in a one-way direction. The primary health centre usually refers a person with major illness to the district hospital for further investigation and management. From here if required patients can be sent to tertiary hospitals. In the rehabilitation sector, the government of India has set up rehabilitation centres at the state capitals to cater to the population of the whole state. These state centres have the rehabilitation facilities to take care of PWD who have severe disability. These PWD approach the state level centre by self-referral or through the Primary Health Centre or district government hospitals. Upon completion of rehabilitation intervention at the state level centres, they are sent back to the community directly. There is no monitoring or follow-up strategy in place for them by these centres. Neither are there any mechanisms for follow-up within the community. The reasons could be heavy caseloads, lack of funds, the vast area of operation, or non-availability of local centres to take over the follow-up.

Follow-up is an important element in the field of rehabilitation. A referral system with an inbuilt follow-up component will be ideal for rehabilitation intervention. One of the tertiary care units in VCBR has been practicing a follow-up strategy for more than a decade and is explained below. (See Box 6.1)

Box 6.1

At the rehabilitation institute, CMC the PWD are being regularly followed up in many ways. The Rehabilitation Institute has a defined geographical area of 100 km radius of Vellore Town for regular follow-up. PWD who complete their rehabilitation intervention and reside within a 100 km radius are enrolled in the database for follow-up. They are visited by the rehabilitation team through home visits and those who need further intervention are referred to the Rehabilitation Institute. Once a year a "Rehab Mela", (annual fair) is organized. Here their problems and needs can be reviewed and addressed. The idea of an annual fair is central to every community in India providing more than just a chance for food and fun; it says something about the community - the enduring nature of such communities, the support found within them and the force for change found there. It is a time when people return to their roots, no matter how far they have to travel. They meet together and the very act of being there says "I am here for you" The Rehab Mela is a 3 day event which includes free medical check-up, investigation and treatment, repair of aids and appliances on the first day. The second day focuses on the 'talents' of the PWD like sports and cultural talents. On the third day, the psycho-spiritual aspects of PWD are explored and addressed. Each year about 150 persons with severe disability participate in the mela. The meeting together of a peer group to exchange views and share experiences has always been a powerful tool. Such meetings may also provide a springboard for coordinated social action. The mela makes use of all these ideas and hopes to bring about change in their communities.

In the context of VCBR, there was a different referral system used against the usual one-way linear direction. It is presented in the next section and discussed in Chapter 8.

6.3 Interaction between community, secondary & tertiary care

VCBR promoted a partnership between the community, secondary and tertiary care centres involved in the project and centred on the PWD as illustrated in the following examples:

The LS for EL referred her to the LCECU for pain management and EL could feel that it helped to improve mobility. Pain was one of the factors that interfered with progress during the intervention by the LS in the community. EL said,

> *"I went there for two or three times...they gave me some tablets...then only I could bend and straighten. The swelling reduced..."*

There were times when the response to intervention by the LS reached a plateau then they felt that a short admission would help the PWD to proceed further. For example, RA was moving around on all fours at the time of LS's first contact. The LS helped her stand with the support of a 'saree' tied to a roof beam and then a parallel bar. The tightness of her thigh muscles and contractures had prevented the LS from proceeding further. RA was referred to the tertiary care centre for a comprehensive rehabilitation. But due to financial reasons, they did not attend even though free food and treatment were offered.

Rehabilitation of a child with multiple disabilities needs special care and infrastructure. Continuing care could be given at the community level provided the support from the specialized centre is assured. KU's parents had been caring and supportive despite the financial strain but often failed to provide appropriate care on time due to this. The tertiary care centre provided concessionary care to the extent possible, but this was insufficient for KU's care. KU's father explained his difficulty in attending the tertiary care centre and buying medicines due to lack of funds. In his own words,

"I could not...whenever they asked me to bring him..when I delay the visit for financial reasons...the doctors scold me....'why did you not come on the date of review?" They give some date for review.. if I don't go on that day...they will scold me...we don't have that help"

Some PWD who were referred to the LCECU/CMC were given special privileges at these centres considering their socio economic background. The LS of AR discussed the health condition of AR with the VCBR team. A team from both LCECU and CMC made a visit to his home. The team observed that he was incapacitated because of multiple health problems including post polio residual paralysis, partial blindness due to an injury, deafness and cough. The team felt that AR would benefit from a short admission at the LCECU. An ambulance was arranged though it was not the usual practice in VCBR and both AR and his wife were admitted to the secondary care centre. Both were investigated, and cared for in the centre. AR was diagnosed to have tuberculosis and malnutrition in addition to his visible disabilities. He was helped to get anti TB drugs through the Government programme (DOTS) and provided with nutritious food. Later he was discharged. The LS made special efforts to encourage him to continue the medication and straighten his contracted legs. She encouraged the neighbours to make wooden parallel bars for his use. He was given a pair of axillary crutches through VCBR. This collective intervention helped AR to become mobile and productive. AR's wife who has problems with her vision, has been relieved of the burden of caring for him. AR's wife comments

"But for Maryamma(LS) perhaps he would not have lived."

DH who had a brain injury following a road traffic accident was admitted in the Neurosurgery department of CMC. He was then sent to the LCECU after acute care management, for further care. At the LCECU, he was linked with the concerned LS for further follow-up. After discharge from the LCECU, the LS continued to follow DH and his family. DH had several episodes of anger with his wife and because of this she was very upset and became emotionally disturbed. The LS helped DH's wife to express her feelings several times. The

LS also motivated DH to be involved in a gainful employment. Since the LS felt that he would benefit from attending the support group for ABI, she referred the family to the group for at the Rehabilitation Institute of CMC. DH said he has gained confidence and had overcome some of his fears through participating in the group.

The above cases clearly demonstrate the importance of the cyclic interaction between the community based efforts and the secondary/tertiary care. It will be incomplete or impossible if any of the services are missing. No services can be under estimated in terms of contribution towards improving the quality of life of PWD.

6.4 Learning from people

In this study, both the secondary care centre (LCECU) and the tertiary care centre (CMC) played important roles in improving the quality of life of PWD. Both centres offered services such as screening, investigation, diagnosis, initiation of treatment, mobility training, supply of aids and appliances, providing counselling and guidance. There were several occasions where the professionals from both the centres acted as 'trainers' for the LS which indirectly influenced the quality of life of PWD. By being part of the training, not only did the trainees (LS) benefit, but also the trainers had an opportunity to discuss the reality of life within these communities. It is clear that some of the knowledge acquired by the professionals from texts (mostly western oriented) is inappropriate or not practical when applied in this context. They need to develop their knowledge and skills based on the felt needs of the wider community. The CBR gives them an opportunity for this.

In VCBR, the LS were encouraged to contribute during the teaching-learning sessions. During the training to identify people with difficulty in seeing, one of the LS suggested that 'picking stones from the rice which is usually adulterated' is a practical method of identifying people with difficulty in seeing. When there was a need for a hand splint for a lady with disability (VM), the concerned LS

suggested using a coconut shell and a stick for correcting the contracture. VM found this a very effective way to improve the contractures in his fingers.

This illustrates that VCBR was able to create an environment that was condusive to mutual learning.

6.5 Reaching the unreached

Among the health related conditions that needed intervention at the LCECU some required regular monitoring by the LCECU. For example, disability due to stroke, which can be rehabilitated in the community requires regular monitoring of hypertension to reduce the likelihood of a second stroke. VI who had a stroke was admitted at the LCECU following a referral by the LS. The LS played a significant role in rehabilitating VI especially in the area of mobility and self care in the community itself. As there was a plateau in the rehabilitation because of her general ill health the LS referred her back to the LCECU. The admission at the LCECU helped VI to control her blood pressure and improved her general health. This resulted in independence in self-care at the time of discharge. In her own words,

> *"After discharge from the hospital, I could take bath on my own and dress myself easily"*

Unfortunately VI did not follow the advice of the LCECU for regular monitoring of blood pressure due to financial reasons. The LS helped her to get medicines for the pain in her body through LCECU but could not help her in getting blood pressure medicines as the doctors wanted to check her BP before prescribing. Some of these problems of access could be addressed through outreach services by the secondary/tertiary care centres.

Economically unreached people with disability or health needs were able to access care or service through VCBR as in the story of AR reported above.

6.6 Summary of Role of Secondary and Tertiary Care in CBR

The multidimensional nature of problems associated with disability demand a variety of approaches for problem solving. Problem solving can take place at the community, secondary care and tertiary care levels.

The referral system in VCBR helped both the PWD and non-disabled people in the community. Because the referral system helped the non-disabled, it enhanced the participation of non-disabled people in disability related activities in the community. Being part of the referral system gave the LS status and recognition in the community.

Many PWD found that the care given at the secondary/tertiary care centres was useful and contributed to the improvement of their QOL. The 'Cyclic referral system' assured follow-up after care in the secondary and tertiary care centres which in turn assured a better QOL for the PWD.

Both the secondary and tertiary care centres gained knowledge about the ground realities of the lives of PWD in their community situations. This learning has enabled them to modify existing management, treatment, and education strategies.

CHAPTER 7 FINDINGS – INTEGRATED MODEL OF CBR

This chapter builds on the previous findings to illustrate the integrated nature of VCBR and how additional sources of support from the community contribute to improve the QOL of PWD. In the previous chapters the focus has been on the the role of LS (Chapter 5) and secondary/tertiary care centres (Chapter 6). Here the fourth proposition that "the QOL of PWD can also be influenced by other sources in the community, apart from the intervention by CBR" will be added in the presentation of two case examples that help to explore the integrated model of CBR.

7.1 Integrated Model

Chapter 5 and 6 demonstrated that the QOL of any individual is multifaceted and depends on a number of factors and that the varied needs and problems of PWD require different resources within the community or secondary and tertiary care facilities. Many domains of QOL have been identified such as physical, psychological, social etc. These domains are interrelated and affect each other. Disability affects the QOL of a person often leading to a poorer QOL than before the disability. Because the various domains of QOL are interrelated, even though disability may only predominantly affect one domain the effects will be seen in many domains. Any attempt to rehabilitate a PWD so as to improve their QOL should take note of this interrelated nature of the domains of QOL. Any individual is a social being living within a wider social network. When a person acquires disability not only their individual QOL but that of their wider network of families and community is affected. The QOL of PWD is also influenced by how well the links between the community, secondary/tertiary care centre is established to provide a cyclical referral pathway.

The wider community does have an influence on the QOL of PWD. Effective use of positive influence and focused intervention on the negative influence of the wider community would also enhance the QOL of PWD.

Two case examples will now be discussed as examples of an integrated model of CBR. The findings demonstrate the way in which disability and intervention affected the QOL of PWD, using a framework that looks at the domains of QOL of the PWD before disability, after disability and after intervention.

7.1.1 Example 1 (AN's story)

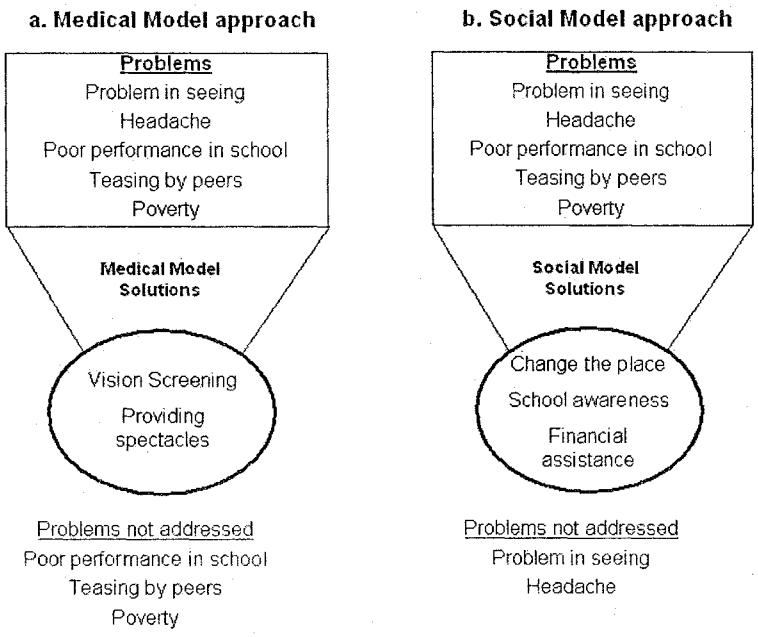
AN is a eleven year old boy studying in a primary school. He had difficulty in seeing and headache leading to poor performance in studies. His class teacher identified his difficulty in seeing and referred him to an eye camp. Following screening at the camp was referred to the eye hospital for further investigation, diagnosis and treatment/rehabilitation. He was prescribed spectacles. As his parents are daily wage labourers, and could not afford the spectacles, the LS assisted AN to get free spectacles through VCBR. The spectacles were found to be useful in improving his eyesight and his headache disappeared. But some of his peers teased him about the use of spectacles and he felt upset about it. There was also a risk of breaking the spectacles while playing. The teacher counselled his friends not to tease AN. She also took special efforts to safeguard the spectacles during his playtime. The influence of this process on AN's QOL is illustrated in Fig 7.1

Figure 7.1 The Framework of QOL domains of AN before and after disability

QOL domains	Pre-disability status	Post-disability status	Post intervention
Physical	Good eye sight Good general health	Difficulty seeing Headache	Could see well Free from headache
Psychological			Upset by peer's response to using the spectacles
Social - immediate (Family)	Family of 4 persons Supportive family	Mother understands AN's problem of seeing but felt helpless	
Social - wider (neighbours, friends, relatives, school, teachers, government)	Attending school	Teacher identified his difficulty in seeing Teacher referred him to an eye camp	Teacher's sensitive understanding and handling of the situation of AN's difficulty with using spectacles
Economic	Hand to mouth economy	Fear of cost of intervention Family could not afford to buy the spectacles	Free supply of the spectacles by LS through VCBR
Vocational	Good in studies	Could not see the black board Study affected	Could do well in studies
Leisure	Play with friends	Restricted play with friends	Play with friends
Spiritual			

In this case as can be seen, several domains of QOL are affected. Intervention based on the medical model would address the problem of difficulty in seeing and headache only (Fig 7.2a). The intervention would target and rectify the physical problem at which time the contact would be terminated. The intervention might have effects in other domains such as improvement of performance in studies but this is usually not considered as part of the medical management. AN's problem of using the spectacles due to teasing by his friends, may have been unnoticed. Whereas intervention based on the social model would focus on the school environment (both physical and social environment) (Fig 7.2b). The intervention would be related to AN's position in relation to the location of the black board or help with finances, or intervention to tackle problems with peers.

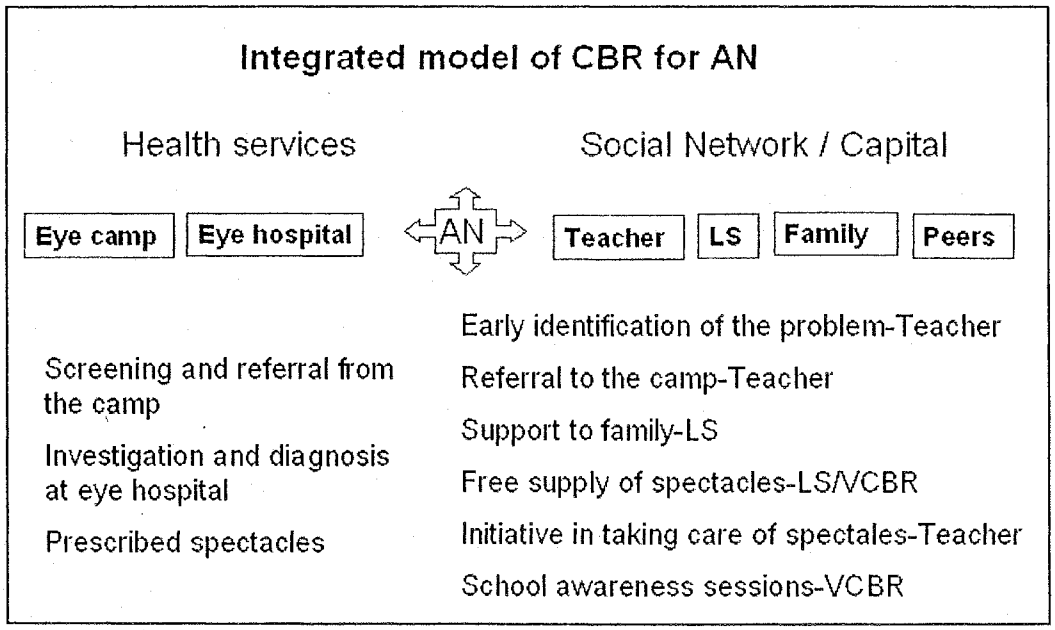
Figure 7.2 Rehabilitation of AN based on discrete approaches
a. Medical b. Social



In reality for his problems are to be holistically addressed AN needed intervention in both areas. Following intervention in VCBR, AN's difficulty seeing improved, leading to improvement in studies. However there were fresh difficulties because of AN's problem in handling the spectacles and teasing by

AN's peers. Both of these problems were addressed by his teacher. She made sure that AN could leave his spectacles with her when he went out to play as well as counselled his peers not to tease him. AN's problem with his peers had not been adequately addressed at the time of study. Since VCBR is an ongoing process, these issues will continue to be addressed. As part of the VCBR, awareness sessions on disability related issues have been conducted in schools in the VCBR coverage area. These awareness sessions may lead to change in attitudes of non-disabled children towards children with disability. In VCBR, AN's problems were addressed in an integrated manner rather than as solely medical or social (Fig 7.3).

Figure 7.3 The effective use of various services available through an integrated model of CBR for AN



In the above example, providing a pair of spectacles for AN would be considered as the cause for the improvement of vision, headache and studies. But there were other positive and negative contextual factors, which influenced his QOL. His teacher who took special care from the identification of his problem through follow-up was a positive resource in this context. His classmates and other children who teased him were negative elements in this

context. There was also an existing mechanism (eye camp) that was used to address his problem. But this could not solve the problem because of other contextual factor i.e. parents could not buy a pair of spectacles because of their poor economic status. At this point in time, the external mechanism (VCBR intervention) was able to solve the problem by providing free spectacles. Another problem emerged from the context immediately after his main problem was solved. Teasing by other children would have discouraged him from using the spectacles, but for the sensitive handling of the situation by his teacher who advised the other children and kept the spectacles safe while he was playing. Considering all the contextual factors (teacher's response to his needs, reaction of the children to his use of aids, poverty of parents) and existing mechanisms (eye camp and referral system) and intervention (free spectacles by VCBR), it is evident that the QOL of AN is influenced by all of them. This shows clearly the importance of contextual factors and mechanisms and makes a strong case that these factors and mechanisms cannot be ignored while measuring the outcome.

The following are the actions taken by different stakeholders addressing various problems of AN in VCBR and in the wider community.

- ✓ Early identification of his difficulty in seeing including testing of vision by the Teacher
- ✓ Referral to the Eye camp by the Teacher
- ✓ Screening of vision and referral to the tertiary care centre at the camp.
- ✓ Further investigation, diagnosis and prescribing spectacles by the team at the tertiary care centre.
- ✓ Discussion with the family regarding their socio-economic condition and support given by the LS.
- ✓ Recommendation and arrangement of free spectacles by the LS.
- ✓ Monitoring and special care given by the Teacher.
- ✓ School awareness sessions on disability issues by the VCBR.

This example clearly shows how the integrated model of VCBR addressed the problems of AN in such a way as to lead to an improvement in QOL. Several people such as the teacher, mother, the LS and institutions such as eye camp,

eye hospital played an important role in this process. This may not have occurred in a purely medical or social model.

7.1.2 Example 2 (VI's story)

VI's main problem was difficulty moving, because of stroke as a result of hypertension. These medical conditions left her dependent on others for her day-to-day activities. Both these conditions require medical care, rehabilitation and lifelong follow-up. Her son was taking care of her with help from a neighbour. This neighbour (lady) visited regularly and helped her with daily activities, especially bathing and dressing. She listened to VI and encouraged her. Although her son was quite happy to look after her, others in the family and VI herself were not happy about this, as they did not think this was a man's job. The family arranged a marriage for VI's elder son with the idea that the daughter-in-law would take care of VI. But the daughter-in-law was not prepared to take care of VI and there was a conflict within the family. Some times VI felt hurt by the reactions of the daughter-in-law. At this point, the VCBR through LS was able to make VI partially independent in self-care activities. For the hypertension, which is a chronic illness and requires regular monitoring, follow-up and lifelong medication, she was offered free care in the secondary care centre. Although she could make use of the offer for a short period of in-patient care she found it difficult to access continuing care due to her physical and financial situation. Because of her difficulty in moving, transport to the secondary care centre and back was beyond her means. However with the help of the LS and the secondary care centre she continued to take the medicines even though regular monitoring was not possible. With time and continuous follow-up by the LS VI's mobility and confidence improved. She is now able to come for regular monitoring of blood pressure to the secondary care centre. The influence of this process on VI's QOL is illustrated in Fig 7.4

VI's problems are medical (difficulty moving and hypertension), social (poor access to health care due to financial constraints) and psychological (feelings of rejection and hurt by the reaction of the daughter-in-law)

Figure 7.4 The Framework of QOL domains of VI before and after disability

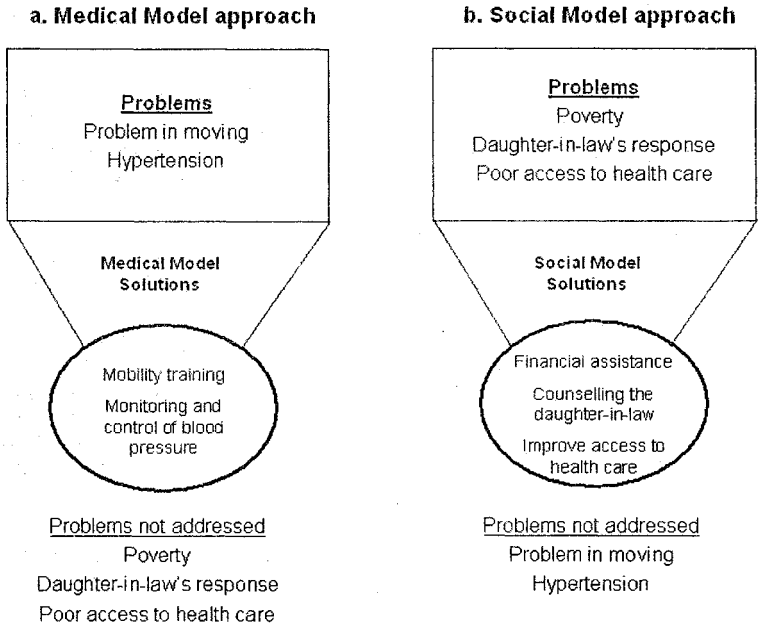
QOL domains	Pre-morbid	Post-morbid	Post intervention
Physical	Healthy Independent Free from illness	Hypertension, Stroke Difficulty in moving Dependent	Taking medicines for hypertension but monitoring not possible Improved mobility Partially independent
Psychological	Happy	Upset about her clawed hand Upset about her daughter in law's reaction to her disability Neighbour as an informal counselor	Relief from upset Improved self confidence
Social immediate (Family)	Lives with her sons Supportive family	Support during crisis by sons Younger son as the care-provider	Support by sons Discrimination by daughter-in-law but basic needs are met by her Younger son free from care giving
Social wider (neighbours, friends, relatives, school, teachers, government)	Good neighbours	Giving bath and assisting in dressing by a neighbour Assistance with day to day self care by neighbour	Neighbour listened to VI and consoled her
Economic	Hand to mouth economy	Economic burden due to acute care management Inability to attend regular health check-ups due to cost of transport	Younger son restarted working Free care offered by LCECU
Vocational	Home making	Younger son and daughter-in-law replaced the role of home making	Home making by daughter-in-law
Leisure	Chat with neighbours	Cut off from most neighbours	Chat with neighbours Watching TV
Spiritual	Faithful Visit to temple	Anger with God Stopped worshiping	

In this case, rehabilitation through the medical model would focus on mobility training in an institution and regular monitoring of blood pressure (Fig 7.5a). In reality, VI could not follow this advice due to financial constraints. VI also had a problem accessing medical care. In this case, although the secondary care centre offered free treatment, VI could not reach the centre as she could not pay the cost of transport.

Intervention through the social model would provide financial assistance through existing social security schemes or engage the family in an income generation activity to improve the socio-economic condition of the family. Architectural barriers in VI's home may have been addressed by using government resources and family counselling to address attitudinal barriers at home counselling would be done. The PWD Act, 1995 would allow for legal action against her daughter-in-law. But VI is not an individual living alone in her house. The dynamics of the relationship between VI's son and her daughter-in-law precludes legal action. Besides there is no guarantee that legal action would lead to a change in the daughter-in-law's attitude (Fig 7.5b).

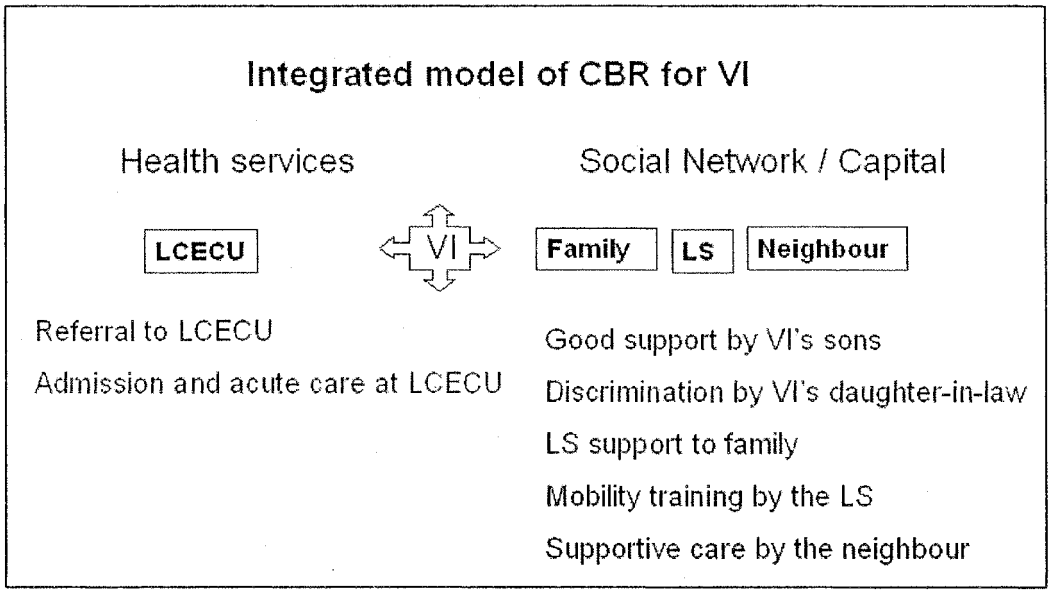
Figure 7.5 Rehabilitation of VI based on discrete approaches

a. Medical b. Social



In VCBR, the LS took special interest in visiting VI regularly despite the long distance from her house. During her visits, the LS taught VI exercises, as well as did the exercises for both affected limbs separately. In the mean time she also worked on mobility in a phased manner from lying to sitting and then to standing and walking with a stick. In fact the whole rehabilitation process took place in the home. This was made possible through the training of the LS (educational strategy). VI's improved mobility made her partially independent in self care activities. She was able to visit the friendly neighbour who used to take care of her and spend time talking to her and play with her children. She herself commented that this helped her to express her distress and feel happier than before. VI was referred to the LCECU for monitoring of blood pressure and was advised to visit the LCECU regularly to monitor her blood pressure. The LCECU has offered her free treatment. But she could not access this care due to the cost of transport. VI's case is an example of how the educational strategy (training of LS) and the use of social network/capital improved the QOL of VI (Fig 7.6)

Figure 7.6 The effective use of various services available through an integrated model of CBR for VI



The integrated model of CBR by VCBR could do the following for VI's problems.

- ✓ Identification and referral to LCECU by the LS
- ✓ Admission at LCECU for acute care management free of cost
- ✓ Mobility training by the LS

The VCBR also recognized that there are other social network/capital, which are available for VI helped to improve the QOL of VI. They are

- ✓ Functional care for VI by a neighbour while she was dependent
- ✓ Good support by her sons

In the above example, mobility training for VI would have been considered as the cause for the improvement in mobility and partial independence in self-care. But there were many other positive and negative contextual elements that influenced the QOL of VI.

VI's case is an example of how multiple resources were involved in the rehabilitation process. The caring neighbour continued to visit her regularly and helped her with bathing and dressing. The commitment of the neighbour without any expectation shows the availability of social network/capital, which CBR programmes should make use of.

7.2 Summary

The above two examples show the multiplicity of problems of PWD and how different resources were used for rehabilitation in VCBR. This in turn led to improvement in the QOL of PWD. Because of the integrated nature of VCBR and the emphasis on education, PWD had multiple options allowing wider choice and better access to resources within and outside the community for the improvement of their QOL.

CHAPTER 8 DISCUSSION

8.1 Introduction

In this chapter, conceptualization of an integrated model of CBR is undertaken based on evidence presented in the previous chapters.

Disability is a complex issue, requiring a variety of rehabilitation measures. CBR is one strategy to address the problems related to disability. There are several models of CBR being followed in various parts of the world based on how disability is viewed and the availability of resources. CBR is a concept, which in practice varies from place to place, depending on the setting. Unlike institution-based approaches, there is no universal model of CBR, which is applicable, everywhere and each CBR programme has to evolve its own strategies and methods as appropriate to its context. It is unlikely that rigid standardization of CBR can ever become possible, as long as there are different cultures. Any attempt at standardization is as good as trying to standardize different cultures and races (Thomas & Thomas, 1998). In this way Thomas and Thomas express the problem which besets experimental evaluation, namely that the context is all important.

This position is central to the realist tradition of philosophy, which suggests that an outcome can be attributed to a mechanism working in a particular context (Pawson and Tilley, 1997). Should the context change then the effect of the mechanism (e.g. an intervention) may be quite different. Strengths, weaknesses and outcomes of any CBR programme would depend on the contexts. Hence any evaluation of different models of CBR must take into account the contextual factors. This defines the particular model from which general principles (mechanisms) can be articulated that can be tested in further contexts of CBR.

The aim of any CBR programme is to improve the QOL of PWD. Evaluation of the interventions would help to know whether the QOL of PWD is improved or not. A review of publications on CBR between 1978 and 2002 identified that there are more studies on theoretical aspects of CBR and less on the evaluation of interventions (Hartley, 2006). Most evaluation studies use quantitative methods such as questionnaires, which provide a limited data set, usually discrete in nature. Qualitative methods allow exploration of both depth and breath of information. Mannan & Turnbull (2007, p.40) recommend that 'future CBR evaluations provide empirical evidence on whether or not it enhances quality of life.' Case studies of specific programs, projects, initiatives, or sites have become an integral part of evaluation research in the latter half of the 20th century, with evaluations analyzing the implementation processes and the outcomes of such initiatives in context (Robert K Yin, 2003a).

This study used a 'case study' design (Robert K Yin, 2003b) that enabled the assessment of QOL both in depth and breath, as well as allowed the voice of the PWD to be heard very clearly. In this study, the design has enabled the researcher to conceptualize and build theory based on the VCBR model.

This study has drawn attention to the multidimensional nature of quality of life and the fact that disability can affect the QOL in many different ways. The domains of QOL such as physical, social, psychological, spiritual, economic, vocational, lifestyle and leisure were affected by disability. The QOL of the PWD improved through the direct services of the LS, referral to secondary and tertiary care centres, and through support given in the community by family and friends.

In this chapter the discussion will address the following main issues on the QOL of PWD:

- ✓ The impact of community level intervention
- ✓ The role of secondary/tertiary care
- ✓ The strength of Social Capital

Finally how these factors are drawn together as an Integrated Model of CBR within the context of Vellore.

8.2 Community level intervention and QOL

The lynchpin of VCBR was the LS and their activites within the community following training. As shown in chapter 5, the majority of interventions took place within the community and included follow-up after referral by the LS. The outcomes of these were predominantly positive on the QOL of PWD.

The communities VCBR engaged with were poor, living a day to day existence, with the economic insecurity of employment within the unorganized sector and little future planning. These factors provided the context for the study.

8.2.1 QOL of vulnerable groups

Social status, traditional roles and cultural reasons, can affect the QOL of particular groups of PWD for example women with disability, children with disability, elderly and people with mental illness. In chapter 5, a number of issues were raised/highlighted regarding them. Women living in VCBR coverage area have to put up with alcoholism, poverty, work pressure and home making (Ref chapter 5 section 5.7.4). When there is a PWD in the family, her role becomes tougher and poses greater challenges. If she herself becomes a PWD, she will be doubly disadvantaged. Women with disability experienced discrimination and stigmatization both as a PWD and as carers. This raises the question 'Is being a woman, a disabling condition?'

Is poverty a disabling condition? Situations of economic deprivation may lead to disabling conditions. Likewise disability reduces the prospect of earning and may lead to poverty forming the viscious cycle of poverty and disability (Albert et al., 2004; Yeo, 2001). Action taken to address the economic problems could prevent or reduce the impact of the disabling conditions. Therefore the scope of the CBR project has to move beyond the narrow definition of disability to include economic deprivation.

CBR programmes should have particular focus on vulnerable sections of the community who have poor QOL.

8.2.2 Intervention and improvement of QOL

Disability affects one or more domains of a person's QOL. There are many possible interventions to improve the QOL of PWD. Identification of the specific domains of QOL that need intervention is the first step in the process. The next step is to plan appropriate intervention keeping in mind that intervention in one domain may show effects in other domains of QOL as well. Different problems of PWD are also interrelated. Any interventions that seek to address problems of PWD and improve their QOL must be similarly of an interwoven nature.

The interviews on the QOL with the PWD whilst covering all domains were weighted towards physical, psychological and economic domains by the interviewees' responses. However there was considerable interaction between the domains

Within the physical domain the themes of mobility, physical activity, dependency, physical illness, comorbidity and health needs , pain and sleep emerged. The physical domain was found to be central to the QOL of the individual PWD studied, influenced and interacted with many of the other domains such as psychological, social, economic and vocational. Mobility especially walking was considered as an important aspect of life by many individuals in the VCBR context. When the disability affected mobility, their emotional, dependency, vocational, and economic statuses were also affected. Likewise intervention on mobility not only produced improvement in mobility, but also helped to improve emotional status, independence and socio-economic status. In chapter 5, examples were given where exercise improved mobility, decreased pain, gave a sense of independence, allowed the return to a vocation, improved a sense of confidence, allowed contribution to household activities and evoked a spiritual response.

A wide range of interventions such as teaching/providing therapy or exercises for PWD, recommending free or subsidized care, counselling, guidance, psychological support, and referral to secondary and tertiary care centres

resulted in improvement in the QOL of PWD. In addition to direct intervention by the LS it was found that institutionalization was also justified as part of CBR for specific circumstances. Flexibility in CBR allowed a wide range of interventions in response to varied needs of PWD taking available resources into account.

8.2.3 Physical and Economic Dependence

Physical and economic dependence are issues for PWD as they not only affect their physical, emotional, social and economic status but also that of the carers. Usually the immediate family members are the carers for the PWD and their caring role is in addition to their routine work. . Dependence sometimes leads to the PWD being considered as a burden. Improvement in self-care leads to independence. This will not only help the PWD but also the carer, who being freed from the caring role for some time will be able to carry out other duties. Sometimes improvement in self-care helps the PWD to think about their future in more positive terms including a vocation. An intervention focusing on vocational independence would improve the economic status of the individual and their value within the family.

In VCBR although intervention focused on independence, whilst some PWD who had temporary disability benefited, the carers of people with severe and long-term disability demonstrated continued burden. Some examples of long-term management are shown within the project but more could be achieved within the community. For example, in another community near Vellore, the parents of children with severe disabilities joined together and established a day care centre called 'NESAM' (See: Box 8.1)

Box 8.1

Nesam is an organization, which was born out of the felt needs of some of the parents of children with disability in Arcot, a small town in the Vellore District. As there were no facilities in the local town, a few parents used to visit the Spastic Society of Tamil Nadu (SPASTN), Chennai, 100 km away, for rehabilitation. Having gone regularly for some time, some of the parents found it impossible to continue to receive regular follow-up services as they could not afford the travel cost and could not spend the time travelling. The staff at SPASTN were willing to train these parents so that they could have a branch at Arcot town. Many parents received training at SPASTN and a branch was opened at Arcot (Nesam) with the direct supervision of SPASTN. In time, the SPASTN felt that Nesam could function on its own and it now functions independently with continued support from SPASTN in the area of training.

This programme demonstrated a power of the community group coming together to organize care and thus improves the management of these children with severe disabilities. The advantages of such efforts are as follows:

Sensitivity

Trained parents are the right people to plan appropriate need based programmes.

Resource

Experienced parents serve as resource for the new parents helping them to come to terms with disability of their children.

Empowerment

Parents of the children with disabilities are empowered with the knowledge, skills related to the rehabilitation of their children and as well as their rights and opportunities.

Respite care would be a solution for some of the parents of children with severe disabilities/multiple disabilities. However this concept has not reached India unlike some other countries. Lack of financial resources, non-availability of trained personnel and lack of institutions for care are some of the reasons. If

the parents' needs are not addressed they might become frustrated and the quality of care given to their children may be compromised.

Such initiatives could also be applied in other communities where there are similar levels of needs albeit other age/disability groups. The LS being local and trained in CBR are ideally placed to help organize such potential initiatives with the community.

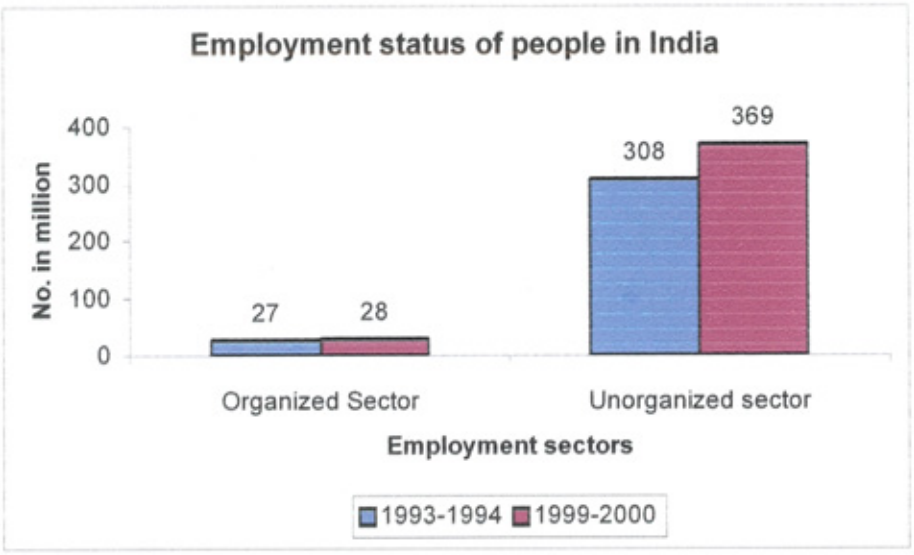
With respect to economic dependence, the poverty-disability cycle is another situation where intervention to reduce disability is possible. The government of India has a scheme for the employment of PWD. The objective of the scheme is to help the PWD to obtain gainful employment either through Special Cells in regular Employment Exchanges or Special Employment Exchanges for the PWD. The Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995 provides for a 3% reservation of identified jobs in government establishments and Public Sector Undertakings (GOI, 1996). As of January 2000, in information made available by the Department of Personnel and Training with respect to 50 Ministries/Departments of the Government of India, the status of filling these posts by PWD against identified posts in various categories is more than 3%. In addition to this the government has provided special provisions for PWD to engage in self-employment ventures.

In VCBR area, most of the people work in unorganized sector and their work involves a lot of unskilled physical labour as a result, their income depends on the availability of work and their ability to access it. The income of a person in VCBR ranges from Rs.30/- to Rs.60/- per day. The Millennium Development Goals (MDG) recommend that the income level of an individual should be a minimum of 1 dollar a day (equivalent to Indian Rs.45/-) (ILO et al., 2004; Secretary-General, 2005). Therefore the income in a family with 5 members should be 5 dollars a day. Considering the socio-economic and vocational factors of people in the VCBR coverage area, achieving this MDG seems to be almost impossible.

Disability adversely affects economic and vocational domains often through physical impairment. In VCBR area, with such a hand to mouth existence any unexpected expenditure related to health/disability shatters the financial stability leading the individual family into severe debt. Such a situation is described as the 'Debt trap' in Chapter 5 Section 5.6.7.

A study done by Monawar Hosain et al (2002) on the impact of disability on the quality of life of PWD in Bangladesh revealed that 79.7% of PWD reported that disability had some negative consequence on their employment. 27.5% of PWD, who were employed could not earn as much as did people who were not disabled. In India, 'The PWD Act, 1995' addresses the rights of PWD who acquire disability during their service in the government sector. No such protection exists in the unorganized sector where majority of people in the country work in unorganized sector. A survey carried out by National Sample Survey Organization in the year 1999-2000 showed that of the 397 million working population in India, about 28 million were in the organized sector and the rest (369 million) were working in the unorganized sector. Compared with a similar survey done in 1993-1994, there was a significant increase in the number of people in the unorganized sector, whereas there was only a minimal increase seen in the organized sector (Fig 8.1).

Figure 8.1 showing the employment status of people in India based on National Sample Survey conducted in 1993-1994 and 1999-2000



The working group constituted by the planning commission of the Government of India for the tenth five year plan broadly classified the social security arrangements in the unorganized sector into four groups as follows:

i) Centrally funded social assistance programmes

ii) Social insurance schemes

iii) Social assistance through welfare funds of Central and State Governments and

iv) Public initiatives

Despite there being several schemes under each group, there is a huge gap in coverage and there is no institutional framework to implement the social security programmes in this sector (GOI, 2001).

A pension scheme is available for widows and senior citizens who are not supported by their families and for PWD who do not receive any other benefits from the government. The formalities required to access these benefit are tiresome and there is a big waiting list as the resources allocated for this scheme are limited. There are occasions where eligible people die before their turn comes. It is also compounded by corruption, which is a part of daily life in India. Even when a PWD is in receipt of monthly pension of Rs.400/-, there is a practice of deducting Rs.20/- from each person by the postman who makes the delivery. An evaluation study done by a group of students from University of South Australia on the rehabilitation services of a rural outreach department of CMC also brought out similar practice of deducting Rs.10/- from each PWD by the postman (Riehl, Ashton, & Drinkell, 2005). The interwoven nature of poverty and disability demands that CBR should be seen as a development issue as suggested in the joint position paper by ILO, UNESCO and WHO (ILO et al., 2004). Economic issues are complex and dealing with them requires working with a range of options from subsidy to vocational rehabilitation.

Vocation provides a person with an income and facilitates the fruitful use of his/her time. In addition to this, it gives a person status in society. Income, the effective use of time and an identity help to improve the quality of life of a PWD. The researcher has been involved in a vocational rehabilitation programme for

persons with severe disabilities at the Rehabilitation Institute. His experience shows that the survival of the persons with severe disability is closely linked with their ability to contribute to the family income. The family usually neglects those who do not earn anything. Some lose their self-respect and become dependent because of unemployment. This results in some people killing themselves rather than continuing to be a 'burden' on their relatives (Guru Nagarajan et al., 1995). In developing countries, the rates of unemployment and underemployment among the disabled are undoubtedly higher than non-disabled people (ILO et al., 2004).

In VCBR, recognizing the vocational and economic needs of PWD, several attempts were taken in terms of vocational guidance, counselling, training and facilitating some PWD in obtaining a pension from the government. This study demonstrated successful outcomes following intervention in these areas.

8.2.4 Psychological and Emotional aspects of PWD

Harmony of mind, body and spirit is crucial to keep a person in good health (Spector, 2002). People with physical disabilities are at risk of developing emotional and psychological problems because of the pressure the physical disability places on them (Turner & Noh, 1988). Mental health problems are an important source of burden worldwide (Ustun, 1999). In India, the proportion of trained mental health professionals to detect and treat people with common mental disorders is inadequate (Khandelwal, Jhingan, Ramesh, Gupta, & Srivastava, 2004). Just one psychiatrist is available for every 300,000 population in India. The Psychiatrist-population ratio in rural areas is estimated to be less than one for every million (Dhar, 2007). The WHO has recommended that the treatment for common mental disorders should be based in primary care (WHO, 2001b). Therefore it is entirely appropriate to consider community mental health within the realm of CBR. In this study, people with mental illness were not included for interviews but VCBR through the LS has made referral to the tertiary psychiatry unit and took part in follow-up in the community.

Psychological distress following a disability is more common among persons who acquire a disability later in their life than people who are born with a disability or acquired a disability early in their childhood (Bishop, 2005). The LS provided considerable informal counselling and emotional support to adults with acquired physical disability and their carers. This activity was integral to the LS's role, their presence and availability within the community, which enabled the timely intervention at the time of crisis (see Chapter 5, section 5.4.3).

Depression is the fourth leading cause of disease burden, accounting for 4.4% of total disability adjusted life years (DALYs) in the year 2000, and it causes the largest amount of non-fatal burden, accounting for almost 12% of all total years lived with disability worldwide; however 76.3% to 85.4% in less developed countries receive no treatment (Ustun, Ayuso-Mateos, Chatterji, Mathers, & Murray, 2004). Depression can be prevented if the early symptoms are recognized in advance. As shown above, the LS have demonstrated some basic skills in the area of community mental health, there is potential for further skill development in this area, which could fulfil the recommendation by the WHO to locate services in primary care (WHO, 2001b).

8.2.5 Summary

The interrelationship of all domains of QOL is evident and whilst in this study the majority of disability tends to impact directly in the physical domain, major effects ripple into the psychological, economic and vocational areas. In turn this ripple spreads out to all areas. The LS approach is to identify the main domain affected in the first place for intervention, but the effects of that intervention reflect the interwoven nature of the domains and hence a positive impact is seen generally in the individual QOL.

A key element of the LS intervention is the recognition that some problems of PWD require expert care beyond their capabilities in the community. Referral to appropriate institutions to address some problems of PWD is an important principle and practice followed in many CBR programmes (Helander et al., 1989; Stubbs, 2001) and is clearly dependent on the context. Likewise the

parthership with secondary and tertiary care and other institutions provides a continued care within the community following expert intervention. These issues of referral and follow-up will be further explored in the next section.

In VCBR the use of local resources, which included both people and materials was helpful in improving the QOL of PWD. Innovative use of locally available materials such as old saree as a support for climbing, bamboo for making a parallel bar, coconut shell as a splint was found to be effective in the rehabilitation process. Involving local people for the rehabilitation of PWD is an attempt at wider community participation. As more and more non-disabled people become a part of CBR, a more inclusive society becomes possible. The significance of the involvement of the wider community will be explored later in this chapter.

8.3 Secondary/Tertiary care and QOL of PWD

Some problems of PWD require expert care, which is beyond the capability of the LS or the community. How to carry out appropriate referral was an important part of the training in VCBR. The LS' knowledge about and association with resources in the secondary and tertiary care centres and government were found to be useful in improving the QOL of some PWD who required intervention outside of the community. The ability of the LS to address complex needs of PWD, which are beyond the scope of local resources, was enhanced through VCBR.

In VCBR, the Low Cost Effective Care Unit (LCECU) acted as the secondary care centre and the Christian Medical College Hospital including various departments like PMR, Ophthalmology, ENT and Psychiatry acted as the tertiary care centre.

8.3.1 Linking with secondary/tertiary care centre

The intervention at secondary and tertiary care centre depends on various factors. The severity, complexity, multiplicity, type and nature of the disabling condition influenced referral. For example in VCBR among the PWD who were having difficulty seeing, the majority presented with complaints of cataract, and other medical problems like watering of eyes, redness of eyes and head ache. All these require intervention in a tertiary care centre and the roles of LS in this situation are identification, referral to the camp/tertiary care centre and follow-up after intervention. In VCBR, while providing intervention at the community, the LS used the services of secondary/tertiary care centres whenever required and this led to improvement in the QOL of that PWD.

In addition to the referral, arranging/recommending free/subsidised treatment at the secondary/tertiary care centres becomes necessary considering the socio-economic status of PWD. Many PWD were helped to complete their rehabilitation by receiving free/subsidised treatment through the VCBR. The PWD who received support from the VCBR perceived it as useful and timely help.

Linking with secondary/tertiary care centres was found to have improved the access to general health care for the PWD. There were some PWD who had general health problems who were diagnosed and treated appropriately in the secondary care centre.

General health care is a need for both PWD and non-disabled people in a poor urban community. However because of the insecurity of occupation and wage, the nature of work, the poor availability and cost of appropriate health services, accessing health care is not a priority for poor urban people. In such a situation providing primary care and linking with secondary and tertiary care centres would be a support for medical care. The medical needs of individual people with disability who have multiple problems would be better addressed in the secondary or tertiary care centres.

8.3.2 Access to secondary/tertiary care services

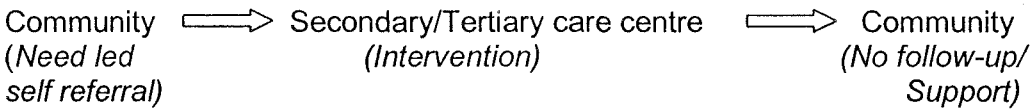
There were some PWD who required care at the secondary or tertiary care centres but could not use the services for various reasons. These included social and financial reasons as they either could not afford the travel costs or were unable to find a family member to accompany them.

Women with disability find it more difficult to access secondary/tertiary care centres than men with disability. This further supports finding of the discrimination of women discussed earlier. CBR intervention should have a particular focus on these marginalized groups such as women and elderly people with disability. Their specific problems may be studied in detail so as to plan appropriate strategies. Initiating outreach services from an institution to the community as part of CBR in addition to setting up of a referral system would ensure maximum coverage and enable prevention of specific disabilities (e.g. second stroke).

8.3.3 The Referral System

Prior to VCBR there was no continuity of care available within these communities. The normal pattern of access was one of self-referral by some, where they were able from the community to the secondary/tertiary care centre depending on the needs and there was no monitoring/follow-up for the PWD following intervention at these centres. This is a disjointed one-way referral system (Fig 8.2), which is likely to serve few of the many PWD in need.

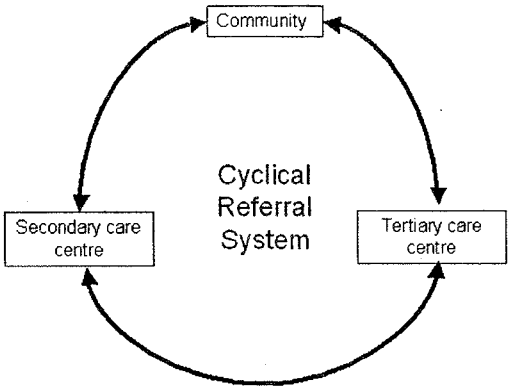
Figure 8.2 Disjointed One Way Referral System



In VCBR, the referral for care to secondary/tertiary care centre from the community was done by the LS. Likewise from the secondary/tertiary care centre to the LS in the community following intervention for further follow-

up/support. The referral system followed in VCBR is cyclical rather than one-way (Fig 8.3). The key feature of this system is active interaction between the service providers (LS and Secondary/Tertiary Care centres).

Figure 8.3 The Cyclical Referral System



The example of DH given in chapter 6 section 6.3 show this interaction illustrating how well his rehabilitation and care were managed by the LS. She became involved during his acute care in the LCECU and continued to visit and support him and his family in the community and was able to link into further support systems (ABI support group and his employer). AR and MU described earlier provide further case examples (Ref Chapter 6 Section 6.3).

A referral system with an inbuilt follow-up strategy was found effective in providing rehabilitation and improving the QOL of PWD. Any rehabilitation whether it is institution based or community based with such a cyclical referral system established would potentially reach all PWD and address their problems and needs in time. Through this referral system, an assured follow-up and chance for getting real feed back are possible. The follow-up of the 'home programme' can be done easily for those who need it when they are discharged from the institution. Early referral for those who may need readmission or review at the tertiary care centre can be initiated.

The availability of the referral system for non-disabled people could encourage community participation in CBR programmes. At the same time it is possible

that the LS could become overwhelmed by the needs of the non-disabled community. In VCBR the LS were sensitized to these possibilities and encouraged to keep a balance between the needs of the PWD and others. The linking of the community, the secondary and tertiary care centres proved to be of benefit to all the groups. The PWD received appropriate good quality care that improved their QOL. The general community benefited by better access to health care. The secondary and tertiary care centres benefited from learning about the ground realities in the lives of PWD.

The 'Cyclical referral system' shows that the needs of PWD were addressed appropriately. The interaction between community, secondary and tertiary care centres was found to be effective in improving the QOL of PWD.

8.3.4 Mutual Learning

CBR encourages the concept of 'learn from people' but in practice there are barriers in doing so. The main barrier is with the mindset of the professionals as they see themselves as experts and trainers not as learners. The PWD are seen as receivers of some benefits from them. Most of the time they do not recognize what they receive from the PWD. This is in contrast to Schon's concepts of professional learning encompassed by reflective practice based learning (Schon D, 1983). There was a time when people started lobbying about the disadvantages of 'top-down' approach in CBR (Werner, 2002), and 'bottom-up' approach was favoured. But in both approaches the community has been given a very low status (down or bottom). As long as the attitude of the professionals/experts towards the community remains negative, it is very difficult to learn from people. In VCBR, recognizing this, the trainers were motivated to be sensitive to understand and learn from the knowledge base of the community. 'Learning from people' is emphasised by David Werner in his book called "Nothing about us without us" where he remarked that the professionals should be 'partners in problem solving' (Werner, 1998a). In this study there is clear evidence of many situations (eg. vision screening, use of coconut shell as splint: ref section 2.3.5), where the professionals have learnt from the LS, PWD and the wider community. This has been a great strength of

the development of the VCBR enableing the growth of mutual respect and strong partherships.

8.3.5 Resource Mapping

In some places as in VCBR the implementing organizations of CBR themselves act as secondary or tertiary care providing centres. For a small non-governmental organization, the real challenge would be to identify and liaise with existing organizations for referral of PWD who require special and advanced rehabilitation services. Resource mapping for possible links to meet the various needs of PWD would be necessary and should not stop with identification of resources but it should be used to create new partnerships for community building. If the link is not made and a good referral system is not in place with other institutions, the CBR project will not be in a position to cover all problems of PWD from the community. In other words, by neglecting a group of PWD whose problems could not be addressed in the community the CBR project would be forced to discriminate against one group of PWD in preference to another in the community.

At an international conference on CBR in Netherlands in 2002, it was recommended that the UN organisations should establish structures to facilitate an exchange of information between CBR and related programmes, i.e. Mental Health programmes, Primary Health Care, community development programmes (DCDD, 2002). The range and magnitude of problems and needs of PWD are vast and the coverage of all PWD by a CBR programme in isolation is not practical.

8.3.6 Summary

In VCBR, evaluation of the care pathways revealed several initiatives which facilitated the process of referral such as subsidy for rehabilitation at the institution, free aids and appliances, including the LS as part of the decision making team for that particular PWD, empowering the LS to recommend extra support to deserving PWD whom they have referred. The LS provided

appropriate follow-up, which included home visits, dressings of wounds, supervision of medications or any other suggested recommendations from the referral centres. All these activities contributed towards a strong and effective referral system.

The interaction between the LS, PWD, Secondary and Tertiary care centres established in a cyclic referral model has demonstrated benefits to all stakeholders. For the PWD, this system enabled a continuity of care and supported management both within the community and in secondary/tertiary care centres. The LS in her pivotal position felt empowered and her status within the community was enhanced. For the professionals, their practice was developed by their interaction with the LS and the PWD in their community context. The wider community also benefited from improved access to health care.

In VCBR both secondary care centre and tertiary care centres have a significant role in improving the quality of life of PWD and their families. Flexibility, commitment to the poor and deserving, support of the LS, good infrastructure, opportunities for mutual learning and willingness to share the resources were some of the positive factors exhibited by both centres.

The multidimensional nature of problems associated with disability demand a variety of approaches for problem solving. Problem solving can take place at the community, secondary care and tertiary care levels. The wider community context also influences the QOL of PWD and this will be explored in the next section.

8.4 Social capital and QOL of PWD

A PWD is not alone but part of the family which in turn is part of the wider community and his/her relationship with others and vice versa influences their QOL. The WHO promoted CBR with the expectation of developing rehabilitation resources through trained family members (Helander et al., 1989).

According to Dalal (2002, p.21), "Disability rehabilitation was primarily considered to be a responsibility of the family. Large and extended Indian families provided essential physical, emotional and economic support to its members with disabilities. Being cohesive and stable social units, families provided an identity and a sense of security to its members, irrespective of their physical disabilities." Disability not only affects the individual but the family as well. Indeed if all the family memers are involved with the disability then a much larger percentage (may be 35 – 40%) of the community are likely to be affected (Elwan, 1999). However families are not isolated social units but are part of a wider network of society. In consequence, resources can be mobilized both within the family and in the wider network. An important determinant of the success of health related interventions is the extent to which they mobilize existing sources of social capital or encourage the development of new sources of social capital (Gregson, Terciera, Mushati, Nyamukapa, & Campbell, 2004). This is true for CBR intervention as well.

In this study, it was found that the involvement of other people either directly or indirectly in the lives of PWD influenced their QOL. Friends, neighbours, teachers, pawnbroker, relatives and other institutions including Government were some of the social network resources for the PWD. The WHO has recognized the significant role of school teachers in rehabilitation of PWD and there is a training manual exclusively for school teachers (Helander et al., 1989).

8.4.1 Social Capital (Friends/Peers, Neighbours, Teachers)

In this study, friends have both positive and negative influence in the lives of PWD. Friends' visits and their consoling words encourage some PWD to have confidence in their life. In addition to providing moral, physical and spiritual support, they also provide financial help during the crisis. The neighbours in this study demonstrated a 'go the second mile' practice. The type of help by the neighbours to the PWD ranged from the identification of PWD during survey, rendering physical and financial help to the PWD sharing their distress by listening to them. Listening may not solve the problem but certainly helps the

PWD to view the problem from other angles and help them to see better their possible options. It could prevent depression, suicide etc. In addition to specific help rendered by friends, relatives and neighbours, their regular visits to PWD helped to improve their self-esteem, and assured them that their lives had a purpose despite the disability. Other than friends and neighbours a teacher and a pawnbroker played significant role for improving the QOL of some PWD.

Where there are positive actions of support to PWD as in the case of VCBR, they should be published. This could be to counter discriminative and negative actions that are more frequently published. Such publicity in literature could discourage non-disabled people from participating in the rehabilitation process and encourage the PWD to develop antagonistic attitudes towards non-disabled people. Ultimately a society with two marked communities (disabled and non-disabled) will be added to the existing caste, and religion based groups.

8.4.2 Reaction to disability in the wider community

In general stigma, discrimination, negative attitude, and exclusion are a part of societal response to disability. How the wider community looks at PWD or treats them reflects their attitudes. In VCBR, the general response to disability in the wider community is encouraging.

Social science research on stigma has grown dramatically over the past two decades, particularly in social psychology, where researchers have elucidated the ways in which people construct cognitive categories and link those categories to stereotyped beliefs. In the midst of this growth, the concept of stigma has been criticized as being too vaguely defined and individually focused. In response to these criticisms, Link & Phelan (2001) define stigma as the co-occurrence of its components – labeling, stereotyping, separation, status loss, and discrimination – and further indicate that for stigmatization to occur, power must be exercised. The concept of stigma which they construct has implications for understanding several core issues in stigma research, ranging from the definition of the concept to the reasons stigma sometimes represents a very persistent predicament in the lives of persons affected by it.

As there are so many stigmatized circumstances and because stigmatizing processes can affect multiple domains of people's lives, stigmatization probably has a major bearing in such areas as earnings, housing, criminal involvement, health, and life itself. It follows that social scientists who are interested in understanding the distribution of such life chances should also be interested in stigma (Link & Phelan, 2001). Scambler and Hopkins proposed two distinct forms of stigma: enacted stigma and felt stigma. Enacted stigma refers to episodes of discrimination against disabled people, solely on the grounds of social unacceptability, while felt stigma refers to the shame associated with having a disability and the fear of enacted stigma (Kassah, 1998). A study conducted to examine the direct and vicarious impact of the social processes of felt and enacted stigma and their impact on the lives of individuals with disabilities and their families indicated that PWD find varied and creative ways to resist and actively counter the negative effects of stigma in their lives (Green, Davis, Karshmer, Marsh, & Straight, 2005).

In VCBR, none of the PWD interviewed felt that their status or respect in the community had changed due to the disability. Nine of the 11 PWD who responded said that there was no teasing or ill treatment or any hurting comments about their disability by the adults in the community. In fact many said that the people generally feel sympathy (pavam /irakkam) towards them. The others had some experience of discrimination (See Sections 5.3.1.5 and 5.3.2.3). Lang (2001, p.9) in a group interview with PWD in a CBR programme at South India reported, "People are afraid to come in contact with disabled people. They think that disability is contagious. Some people in the community tell others to avoid disabled people because they might also attract the bad luck of the disabled person and the family."

In VCBR, there was no significant stigmatization and discrimination found among the wider community towards PWD. However the reaction of the non-disabled children towards children with disability was different from the adults. The children demonstrated negative attitudes and teasing of other children with disabilities as seen in the example described in detail in the previous chapter on Integrated Model. Why do children behave in this way? Is this because the

current generation are not exposed to the needs and abilities of PWD? Is there any problem with the educational system? Since the current educational system recommends inclusive education, where is the problem? The older generation would have grown up in a joint family system where they would have had good exposure to the needs and abilities of PWD in their family circle. In the past, the PWD and other marginalized people like widows and elderly were supported by the family members because of the existence of joint family system. This study found that the joint family system is not evident in VCBR coverage area. Children growing up in nuclear families are less likely to be exposed to PWD as their parents and grand parents.

In India, both the government and some responsible organizations have realized the issue of stigmatization, which is attached of some illness/disability. For example, a person with leprosy was called as 'leper' in early days. The Government of India banned using this term and suggested calling them 'a person with leprosy' and this was later renamed as Hansen's disease. CBR should recognize the deeper cultural components especially language related to creating stigma and discriminative actions against PWD.

This study showed that children need to be educated in order to develop positive attitude towards PWD. Working with children in the community to remove fear of difference, and stigma is a challenge that CBR must address. Stigmatization of disability is believed to be a part of the dynamics of community life. There is no doubt that stigma leads to exclusion and discrimination. CBR interventions should not only prepare the individual PWD to mix with the wider community, but must also create awareness and sensitize the wider community to the problems, needs and abilities of PWD. Specially focussing on children would enable long-term change in attitudes to PWD in society. Awareness programmes were conducted through schools and in the local community in VCBR. In one area non-disabled children were encouraged to participate in the network meetings of PWD. More exposure of non-disabled children to children with disabilities would help to develop positive attitudes towards PWD. The concept of inclusive education also supports this. The manual for promoting inclusive education under the Sarva Shiksha Abhiyan

scheme states "children who learn together, learn to live together" (Tripathi, 2003, p.2).

The researcher appreciates the Government's initiative in the area of non-discrimination of PWD by enacting the PWD Act in India. In this Act, discrimination of PWD in the transport system, on the roads, in the built environment and in government employment were specifically discussed (GOI, 1996). There is no doubt that this legal code will encourage non-discrimination. The researcher suggests that CBR should sensitise the wider community about disability and take steps to develop positive attitude towards PWD.

8.4.3 Friends of PWD

In VCBR, the move towards forming a forum called "Friends of PWD" was an encouraging part of the CBR. Giving emphasis to the welfare of PWD by focussing on them as a special group may produce short-term gains. However, in the long run it may encourage the promotion of PWD as a separate group, with poor integration into mainstream society. The challenge in this process is to achieve a balance between PWD and the rest of the community. In society, each individual is discrete and has to lead a separate life albeit within family and community, especially in India with its varied cultures and languages. The social structure in India is pluralistic and diverse. Both PWD and non-disabled are part of this diversity. It is the responsibility of any CBR programme to enhance the relationship between the PWD and the non-disabled people. Attitudes towards disability and PWD are generally formed based on the individual's exposure and experience. In the forum of 'Friends of PWD', abilities and special needs of PWD are exposed to the non-disabled population in structured training programmes or in organized meetings. By doing this, not only do the non-disabled people understand the abilities and needs of PWD, but also PWD get opportunities to know that there are people who love them and are willing to support them. Well-informed networks of people without disability will be able to support the PWD when they raise their voices for equal rights and opportunities. All people experience the inability to do some thing at some point in their life. Therefore we could say that everybody will at some time

be disabled. So fora like Friends of PWD could be beneficial to both PWD and 'non-disabled' people. Clearly the PWD may be benefit by improved acceptance from the non-disabled and they in turn learn from the PWD about coping strategies.

8.5 Integrated Model of CBR

The concept of an integrated model has been aired a number of times in the literature under variety of labels eg. Biopsychosocial model (WHO, 2001a), partnership model (Barnes M.P & Ward A.B, 2000a) or implied through collaboration or working together (Boyce & Johnston, 1998; ILO et al., 2004). Cole suggests 'It would seem that in the context of disability, neither model (medical and social model) provides a complete approach and that an integrated approach, encompassing elements from both models will best serve to meet the needs of people with disabilities, their carers and communities' (Cole K, 1999, p.2). The joint position paper on CBR states that CBR will not work if sectors such as social sector (disability pension, aids and adaptations, vocational training and employment), health sector, educational sector, vocational and labour sector, NGOs and Media work in isolation. It further encourages creating conditions for multisectoral collaboration to advance CBR within community development (ILO et al., 2004) . O'Toole and John (1991, p.50) suggested that "the rehabilitation professionals should take up the challenge of reconciling the debate between the various forms of service provision and offer a more realistic model to meet the pressing needs especially in developing countries." A study done in rural Bangaladesh to examine the impact of disability on the QOL of PWD revealed that disability had a devastating effect on the QOL of PWD and recommends that a combination of educational, economic and intensive rehabilitation measures should be implemented to make the PWD self reliant (Monawar Hosain et al., 2002). Although several combined models have been proposed for rehabilitation none of these has yet been convincingly tested.

This study found that an integrated model of CBR helped to improve the QOL of PWD.

The QOL of any individual is multifaceted and depends on a number of factors. Many domains of QOL have been identified such as physical, psychological, social etc. These domains are interrelated and affect each other. Disability affects the QOL of a person often leading to a poorer QOL than before the disability. Because the various domains of QOL are interrelated, even though disability may only predominantly affect one domain the effects will be seen in many domains. Any attempt to rehabilitate a PWD so as to improve their QOL should take note of this interrelated nature of the domains of QOL. Any individual is a social being living within a wider social network. When a person acquires disability not only their individual QOL but that of their wider network of families and community is affected. Hence the multiple effects of the disability require the needs-led responsive approach demonstrated by VCBR within the integrated model.

The varied needs and problems of PWD require different resources within the community or secondary and tertiary care facilities. The wider community does have an influence on the QOL of PWD. Effective use of positive influence and focused intervention on the negative influence of the wider community should also be part of any rehabilitation intervention.
The examples given in chapter 7 show the typical multiplicity of problems of PWD and how different resources were used for rehabilitation in VCBR. This in turn led to improvement in the QOL of PWD.

Traditional models of evaluation tend to focus mainly on the intervention and outcomes alone, without looking at the context. This study used the realist approach, which takes note of the contextual elements in the evaluation of the case study materials. The realist paradigm allowed the researcher to study the mechanisms and outcomes within the particular context of VCBR and highlighted the integrated nature of VCBR.

The VCBR operated in poorer areas of Vellore Town where people live in congested and uneven terrain. Many of them do not own the land or house and live in public property. Most of the people's jobs depend on their physical strength. Smoking and alcohol abuse are common among men in this area. In times of crisis, people usually help each other. Some of the needs and problems of PWD were addressed in this way. The multidimensional nature of problems of PWD influences the various domains of their QOL. These problems are different depending on the type of disability, age group and sex. Among the PWD, some had good social support some did not. Some of the PWD were aware of the social security benefits provided by the government and some did not know. Among those who were aware, some had availed of the social security benefits by themselves.

The selected volunteers were trained in various aspects of disability and rehabilitation. The educational strategy used in VCBR not only improved their knowledge and skills but also improved their social status in the community and the overall knowledge of the community. The training helped them to identify the PWD, their needs, existing resources available within the community and helped to address most of these needs within the community. It also helped them to refer the PWD appropriately. The referral system, which was set up as part of VCBR helped the PWD in many ways and also empowered the LS. Mutual interaction, which occurred between the referral centres and the LS (cyclic referral system) enhanced the accessibility to many resources for the PWD.

8.6 Summary

This study has highlighted the multidimensional nature of the various domains of QOL of PWD. It has also brought to light the significance of the links between the PWD, their families, the wider community and other institutionsand its impact on their QOL. Understanding and making full use of this reality would maximise the potential of any rehabilitation intervention. VCBR as an integrated model has shown that this is eminently possible.

CHAPTER 9 CONCLUSION

In conclusion, the VCBR has demonstrated the success of the integrated model on improving the QOL of PWD. It has shown:

- ✓ ***Integration at the level of the individual*** – achieved through education of volunteers (LS) from the community. Power from its traditionally held position with the professionals has been shared in partnership with the LS and the PWD

- ✓ ***Integration at the level of service*** – better access to resources within primary, secondary and tertiary care through the services provided by the LS in the community and the cyclic referral system thus maximizing coverage of PWD within the community

- ✓ ***Integration at the level of society*** – effective identification of multiple options available to the PWD to facilitate better partnerships within the community

The key features of this approach, which could be explored in other contexts, are:

- ✓ Deprofessionalization with a shift from direct service provider to enabler (trainer)
- ✓ A partnership based teaching–learning approach
- ✓ Community level direct services through non professional volunteers
- ✓ Valuing and building on local knowledge and practice
- ✓ Harnessing local resources
- ✓ Cyclic care pathways with good communication

The success of CBR in the highly supported context of Vellore has been demonstrated above and continues (See Postscript). However the principles derived from this highly supported context could well be applicable in less well resourced environments. The future development of CBR projects in different

contexts need to consider the identification of resources within the community and within existing rehabilitation services to build partnerships based on the above features. In this way the integrated model can be explored in wider contexts and its strengths and weaknesses can be evaluated.

Through this study the researcher suggests the following definition for an integrated model of CBR.

"An integrated model of CBR is a strategy, which uses an educational approach for the improvement of the quality of life of PWD focused on restoration of optimal functioning within their context. It encourages involvement of all sectors such as education, social, economic, health. It builds links between the community, secondary and tertiary care centres for rehabilitation. It utilizes resources within the community encouraging participation of other community members and builds strong networks in the community. An integrated model of CBR aims to provide equal opportunities, social inclusion and universal access to basic amenities for all PWD. It seeks to ensure maximization of their potentials, protection of their rights and their full participation in community affairs."

Based on this study, the researcher suggests the following recommendations, which could be used in the setting up of new CBR programmes.

Any CBR programme should

- ✓ use an integrated approach that seeks to make strong links between social, economic, health and other domains, build networks in the community between the PWD and the non disabled people and between the community and institutions.
- ✓ follow a strategy that empowers all stakeholders with increased knowledge and skills through a flexible and ongoing educational approach.
- ✓ give emphasis to the vulnerable groups within the community
- ✓ develop a cyclic referral system that enables good follow-up and proper feed back

- ✓ use both quantitative and qualitative methods in evaluation.
- ✓ publish information about CBR especially positive experiences which could encourage and motivate others.

Overall QOL of PWD will not improve to its full potential if solutions are mooted from polarized viewpoints. This study found that an integrated model of CBR with an educational strategy, and good links with secondary/tertiary care centres that make use of social network/capital, which is available for the PWD in the community, improved the overall QOL of PWD.

POSTSCRIPT

VCBR plus: Following the active intervention in CBR, which has been explored in this study, the journey has continued. The focus has shifted from the individual PWD to wider community involvement and development including PWD and non-disabled persons. This development has been characterised by the development of: life skills programmes for youth; school education programme on injury prevention, general health and life skills; mothers group meetings; annual networking festival for PWD co-conducted by non-disabled youth; bi-monthly meetings by PWD in the community coordinated by the LS with the support of non-disabled children; running of a special clinic exclusively for PWD and elderly with the support of both PWD, mothers group members and youth. These and other initiatives have facilitated a platform for inclusive development where both PWD and non-disabled persons work together.

GLOSSARY

CBR	Community Based Rehabilitation
CMC	Christian Medical College
DISTAT	Statistics Division of United Nations
DOTS	Directly Observed Treatment Short Course for Tuberculosis
DPO	Disabled People Organization
DRC	District Rehabilitation Centre
ESCAP	Economic and Social Commission for Asia and Pacific Regions
GDP	Gross Domestic Product
GOI	Government of India
HDI	Human Development Index
IBR	Institution Based Rehabilitation
ICF	International Classification of Funtioning, Disability and Health
ICIDH	International Classification of Impairment, Disability and Handicap
IDDC	International Disability and Development Consortium
ILO	International Labour Organization
LCECU	Low Cost Effective Care Unit
LS	Local Supervisor
MDG	Millennium Development Goals
NGO	Non Governmental Organization
NSSO	National Sample Survey Organization
PMR	Physical Medicine and Rehabilitation Department
PWD	Person(s) with Disability
QOL	Quality of Life
SEIQOL	Schedule for the Evaluation of Individual Quality of Life
SWOT	Strengths, Weakness, Opportunities and Threats
UNDP	United Nations Development Programme
UNESCO	United Nations Scientific, Educational and Cultural Organization
VCBR	Vellore Community Based Rehabilitation
WHO	World Health Organization

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APPENDICES

APPENDIX 1

FORM 1 HOUSEHOLD SURVEY FORM IDENTIFICATION OF PWD

Form 1: To record household visits in order to locate people with disabilities

Number of household (see your map) ..... Your name .....

Name of household head ..... Area .....

Total number of people in household ..... Under 15 years .....
Over 15 years .....

Females ..... Males ..... Date .....

■ Ask the household head and other family members the following questions about each household member. Also carry out the disability tests on each person in the household when necessary.

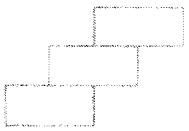
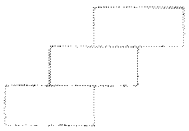
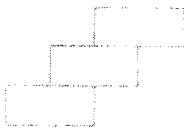
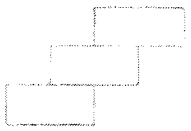
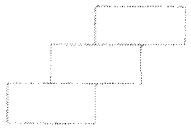
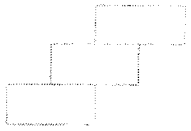
■ Write the answers in the columns provided.

Question	Name of household member with this disability	Age	Sex	How long?
1. Does any person have difficulty seeing?				
2. Does any person have difficulty hearing or speaking?				
3. Does any person have difficulty moving?				
4. Does any person have no feeling in the hands or feet?				
5. Does any person show strange behaviour?				
6. Does any person have fits?				
7. Does any person have difficulty learning?				
8. Does any person have any other disabilities? Name and describe the disability, if you know what it is, next to the person's name.				

APPENDIX 2

FORM 2 IDENTIFICATION OF NEEDS OF PWD

Form 2: To find out if the person needs training and to assess progress		
Name of person with disability: _____		Disability_____
1. Feeds himself or herself? (including eating and drinking)	Alone With some help or sometimes Not at all	☐ ☐ ☐
2. Keeps himself or herself clean? (including washing, bathing, and cleaning teeth)	Alone With some help or sometimes Not at all	☐ ☐ ☐
3. Uses the latrine?	Alone With some help or sometimes Not at all	☐ ☐ ☐
4. Dresses and undresses?	Alone With some help or sometimes Not at all	☐ ☐ ☐
5. Understands simple instructions?	Easily With difficulty Not at all	☐ ☐ ☐
6. Expresses needs?	Easily With difficulty Not at all	☐ ☐ ☐
7. Understands movements and signs for communication?	Easily With difficulty Not at all	☐ ☐ ☐

8. Uses movements and signs for communication which others understand?	Easily With difficulty Not at all	
9. Lip reads?	Easily With difficulty Not at all	
10. Speaks?	Easily With difficulty Not at all	
11. Sits? (including sitting up from lying down)	Alone With help Not at all	
12. Stands? (including standing up from sitting)	Alone With help Not at all	
13. Moves inside the home (including walking, crouching, crawling, or using trolley)	Alone With help of a person Not at all	
14. Moves around the village? (including walking, crouching, crawling, or using trolley)	Alone With help of a person Not at all	
15. Walks at least ten steps?	Alone With bars, frame, crutches or cane With help of a person Not at all	

16. Has aches and pains in the back or the joints?	Very rarely or not at all Sometimes but can still work Disturb work but not sleep Disturb sleep
17. Breast-feeds and grows like other babies?	Yes No
18. Plays like other children of the same age?	Yes No, plays like children below his or her age No, does not play at all
19. Goes to school?	Yes, does normal school work Yes, but does school work below his or her age Yes, but does not do school work No
20. Joins in family activities?	Yes Sometimes Not at all
21. Joins in community activities?	Yes Sometimes Not at all
22. Does household activities?	Yes, all Some, but not all None
23. Has a job or has an income?	Full-time job or income adequate for his or her needs Part-time or seasonal job or some income No job and no income

APPENDIX 3 – LS TRAINING MODULE

Content	Methodology
Introduction to VCBR	Discussion & Exercise
Qualities required for a LS	Discussion & Exercise
Effective communication	Discussion & Role play
House to house survey	Role play & Orientation
How to identify people with strange behaviour	Discussion & Tutorial
How to identify people with difficulty seeing	Discussion & Tutorial
How to identify people with difficulty moving	Discussion, Tutorial, Demonstration & Role play
How to identify people who have no feeling in the hands or feet	Discussion, Tutorial, Demonstration & Role play
How to identify people with difficulty hearing	Discussion, Tutorial, Demonstration & Role play
How to identify people with difficulty speaking	Discussion, Tutorial, Demonstration & Role play
How to identify people who have fits	Discussion & Tutorial
How to identify people with difficulty learning	Discussion & Tutorial
How to identify people who have strange behaviour	Discussion & Tutorial
How to identify people with other disabilities	Discussion & Tutorial
Various kinds of needs (Felt needs, Expressed needs & Assessed needs)	Discussion & Tutorial
Prioritization of needs	Discussion & Tutorial
Who needs training (Form II – WHO)	Discussion & Tutorial
Medication and special measures for people who have fits	Discussion & Tutorial
Safety precautions to be taken by people who have fits	Discussion & Tutorial
Problems of people with difficulty moving	Discussion, Tutorial & Demonstration
How to approach people with disabilities	Discussion, Tutorial & Demonstration
How to prepare a master sheet for survey information	Demonstration & Discussion
How to train the person with difficulty moving to turn over and to sit	Demonstration & Discussion
How to train the person with difficulty moving to move from sitting to standing	Demonstration, Question-Answer & Discussion
How to train the person with difficulty moving to move around	Demonstration, Question-Answer & Discussion
How to identify shortening of limbs following a fracture femur	Demonstration & Discussion
How to prevent pressure sores for people with difficulty moving	Discussion, Demonstration & Snake & Ladder Game

Content	Methodology
Difficulty moving – Exercises to prevent deformities in the limbs	Discussion, Tutorial & Demonstration
Difficulty moving – How to keep the joint in good position	Discussion, Tutorial & Demonstration
How to prepare a referral slip	Discussion
Difficulty moving – step climbing with the support of auxiliary crutches	Demonstration & Role play
Vocational options for PWD	Tutorial & Discussion
Guidelines for referring people to secondary care centre	Discussion & Role play
Difficulty Moving -How to train the person who has aches and pains in the back or the joints to do daily activities	Demonstration & Tutorial
Difficulty moving – How to train the person to take care of herself or himself	Demonstration & Tutorial
Difficulty moving – adaptive devices	Demonstration & Tutorial
Difficulty moving – finger movements	Tutorial
How to prevent back injuries – precautions to be taken while lifting a heavy object	Video show & Discussion
Identification Card from the Government for PWD	Discussion & Tutorial
Difficulty seeing – anatomy & physiology of the eye; how to prevent loss of vision due to Vitamin A deficiency	Discussion, Tutorial & Question-Answer
Difficulty seeing – Testing of vision	Discussion & Tutorial
Difficulty seeing – How to train the person to be independent in self care activities	Discussion & Demonstration
Immunization schedule	Discussion & Tutorial
Difficulty seeing – how to take measurement for a gaiter, height correction cheppal and ankle foot orthosis	Discussion, Tutorial & Demonstration
Difficulty moving – orientation to physical environment	Discussion & Tutorial
Difficulty seeing – Activities of daily living training	Discussion & Demonstration
Vocational rehabilitation of PWD	Tutorial & Visit to a centre
Introduction to prosthesis and orthosis	Tutorial & Demonstration
Introduction to Rehab Mela	Video show & Discussion
Hemiplegia and its implications	Discussion & Demonstration
Sharing of experience – Living with disability	Discussion & Question-answer
Welfare programmes & schemes for PWD by Government	Tutorial & Discussion
Functions of Government office responsible for PWD welfare	Exposure visit & Discussion
Difficulty hearing & speaking - Causes	Tutorial & Discussion
Difficulty understanding – How to train for self care?	Tutorial & Discussion

Content	Methodology
Persons with strange behaviour – How to train the family member?	Tutorial & Discussion
Persons with strange behaviour – How to train the person to be independent in self care	Tutorial, Discussion & Demonstration
Difficulty hearing & speaking – Communication	Tutorial, Discussion & Demonstration
How to train the person who has fits	Tutorial & Discussion
Diarrhoea, Tuberculosis, HIV/AIDS	Tutorial & Discussion
Deformity in the ear	Tutorial & Discussion
Family planning methods	Tutorial & Discussion
Speech and language milestones	Tutorial & Discussion
Aids & appliances for people with difficulty hearing	Demonstration,& Discussion
Developmental milestones of a normal child	Tutorial & Discussion
Approach for joints and back pain	Tutorial, Demonstration & Discussion
Blood donation	Discussion & Demonstration
Rehabilitation of persons with spinal cord injury	Discussion & project
Palliative care	Role play, home visit, Discussion & Tutorial
Rehabilitation of persons with traumatic brain injury	Discussion & Tutorial

APPENDIX 4 – OVERVIEW OF PARTICIPANTS

Table showing overview of all PWD interviewed

Unit	Age	Sex	Edu	Marital status	Etiology	Area of difficulty	Interview duration in minutes
JE	50	M	7	Married	Accident	Moving	178
VN	42	M	9	Married	Accident	Moving	160
UN	46	F	0	Married	Degenerative	Seeing	84
EL	60	F	0	Widow	Accident	Multiple	75
RA	21	F	0	Unmarried	Birth	Moving	83
SU	19	F	4	Unmarried	Infection	Moving	72
VM	70	F	0	Widow	Accident	Moving	114
SK	12	M	0	Unmarried	Birth	Multiple	72
SO	44	M	6	Unmarried	Accident	Multiple	166
VI	50	F	0	Widow	Degenerative	Moving	116
DH	55	M	7	Married	Accident	Multiple	149
UM	2	F	0	Unmarried	Birth	Multiple	64
AR	50	M	0	Married	Infection	Multiple	109
KB	25	F	0	Unmarried	Infection	Seeing	94
KU	5	M	0	Unmarried	Birth	Multiple	88
VA	30	F	0	Married	Degenerative	Moving	147
HB	35	M	9	Married	Accident	Moving	157
MU	45	M	0	Married	Degenerative	Moving	153
AN	12	M	5	Unmarried	Others	Seeing	77
DE	38	F	5	Separated	Accident	Moving	120

JE

JE is 50 years old, living in a slum in Vellore with his wife. His sons and daughters are living separately in the same locality. He worked in the market loading and unloading vegetables. Later he started a tea stall in his slum. He is addicted to alcohol and his family had made many attempts at deaddiction at various centres without much success. His wife was forced to take up employment as a maidservant in a hotel since he was not contributing towards the expenses for day-to-day running of the family.

He had a fall under the influence of alcohol while he was climbing the hill for defecation. The family took him to a traditional bonesetter for care. After the treatment he was left with shortening of the limb and pain.. During the survey the LS identified him as a person with difficulty in moving for 1½ years. In addition to this she found that his general health condition was poor. Since a general health screening camp was being organized at this time through VCBR in Old Town the LS (MJM) referred him to the camp.

At the camp, he was found to have high blood sugar and advised admission for control of diabetes. At the LCECU where he was admitted his sugars were controlled. He was found to have a malunion of his thighbone, which was causing shortening of his limb. This shortening was corrected by giving him special footwear and he was taught to walk with a pair of axillary crutches. After he went home the LS visited him regularly and helped to improve his mobility through an exercise programme, which helped to improve his confidence. Following improvement in his mobility, she identified the need for vocational resettlement. He was helped to restart his tea stall with a donation from a local Church. Although he restarted the tea stall he had difficulty running it for some physical and social reasons. The LS continued to visit and encourage him and in time he was able to restart the tea stall.

VN

VN is a 42-year-old man living with his wife and children in a Vellore slum. His marriage was an inter-religious one and both VN and his wife faced a lot of social problems (social isolation) from their families for a period of time. He worked as a rickshaw puller and also carried loads in the market. His wife is a vegetable vendor in a street market.

He sustained a fracture of his femur while climbing down from a bus after loading a box on the top of the bus. He was taken to a traditional bonesetter for care. After the care he continued to be immobile and dependent for all his day-to-day activities. His family approached the LS asking for her to refer him to CMC.

The LS examined him and found that he had difficulty in moving that was caused by the pain and stiffness of his limb and joints. She worked on these problems and improved his mobility through a regular exercise programme. She visited him everyday and encouraged him to do the exercises regularly. Within a few weeks his pain and stiffness decreased and his mobility improved. As his confidence increased he began to help his wife with her vegetable vending. One interesting feature in this case is that his wife who had learned and assisted with his exercise programme was able to teach these exercises to a person with a similar problem whom she encountered during a visit to her relative in an other town. This person also found the exercise programme to be useful.

UN

UN is a 46-year-old lady who lives with her son in one of the Vellore slums. She has been separated from her husband for many years. Her husband, who works as a security guard in a bank and he gives her a fixed sum of money every month. This helps with some of the day-to-day expenses but is not enough and so she supplements the income by doing beedi work. Her son who is working as a cleaner in a truck is away for 7 to 10 days at a time for his work. Most of the time she lives alone at home.

She had headache and difficulty in seeing which interfered with her work and mobility in the evenings. She took medicines for headache from a local medical shop. She developed abdominal pain as a result of this self-medication.

The LS (NE) visited her at this time and referred her to the tertiary care centre for treatment. She arranged for free spectacles that were recommended as her treatment by the Ophthalmologist through VCBR. With the spectacles UN's vision improved and her headache disappeared.

EL

EL is a 65-year-old lady living with her son in a slum. She lost her husband within a few years of marriage. To take care of her young family she worked in construction sites. Two of her sons are married and living separately and one died at a young age due to an infectious illness. With increasing age she found it hard to do construction work and so she started selling eatables at the side of a street. She lived independently till she fractured her femur because of a fall. She was treated by a traditional bonesetter.

When the LS (SK) visited her, she was found to have difficulty in moving because of stiffness and pain in the fractured limb.

The LS taught her some exercises to reduce the stiffness but found that because of the pain she was unable to do the exercises. So she referred EL to the LCECU for pain management. Once the pain decreased the LS worked with her to improve her mobility and regain independence.

RA

RA is a 23-year-old girl who was born with a disability and has been taken care of by her grand mother since childhood because her parents who live next door are not willing to care for her. She helps her grand mother to do beedi work. The family had taken her for treatment to various centres for delay in development with the expectation that she would be cured. Since this did not happen they gave up trying after few years and left her with her grand mother.

The LS (AJ) found that she had difficulty in moving and was dependant in some of her day-to-day activities. The LS worked with her to improve mobility and demonstrated improvement in standing and walking within a parallel bar. The LS used an old saree hung from a beam as a support for RA to get up to standing position. It took a long time for the

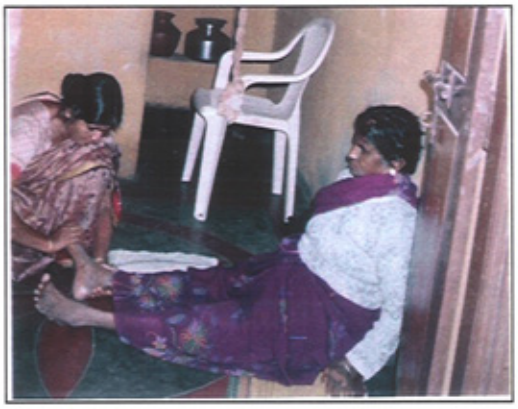
LS to convince the family to make a parallel bar for her near her home so that she could practice walking. A gaiter was given to her through VCBR for stabilizing her knee. Since the VCBR team felt that she would benefit from a comprehensive rehabilitation programme from a tertiary centre she was advised admission free of cost. But her grandmother was unable to use this offer because she could not discontinue working since she was repaying a loan.

SU

SU is an 18 year-old girl who lives with her parents and brothers in a hut. Her parents make and sell brooms for their livelihood. SU studied upto 4th standard and stopped schooling so that she could help her parents to make brooms.

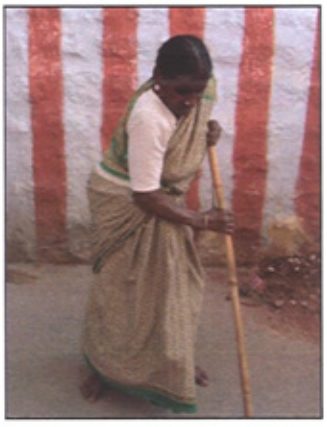
The LS (AJ) identified SU as a person with difficulty moving due to post polio residual paralysis since 5 years of age. The LS visited her several times and found that it would be useful for her future if she learnt a skill. She was referred to the tertiary care centre where she learnt tailoring skills through a 6-month free residential training programme. A free hand sewing machine was arranged through a non-governmental organization at the end of her training. She has been practicing tailoring since then.

VM



VM is a 70-year-old lady who lives independently in her own house, surrounded by her close relatives but has minimal support from them. She is a widow with no children. She brought up her sister's son but he now lives and works in a town, which is far away from Vellore. He gives her some financial support occasionally when he comes to visit. She gets a monthly pension (social security benefit) from the Government with which she manages her day-to-day living. She was independent in all her daily activities.

She had a fracture of femur following a fall. Her son came and took her to the bonesetter for treatment and then to his home. However since his wife was not happy to take care of her she came back to Vellore.

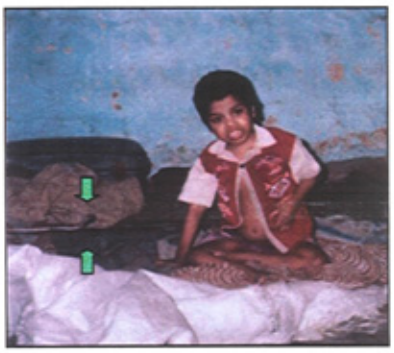


The LS (RUK) identified her as a person with difficulty in moving and pain in the lower limb, who found it difficult to manage her day-to-day activities. The LS started working on her mobility through an exercise programme. She used local resources like a saree as a suspended support for getting up from the floor. The LS also involved a neighbour in the mobility training. With this intervention, VM was able to walk with the support of a stick.

SK

SK is a 12-year-old boy with severe mental retardation who lives with his father and a younger brother. His mother left the family when the children were very young. His father works as a shoemaker. They live in a small hut, which is damaged. His father has difficulty caring for his children as well as managing the household and his work. His addiction to alcohol has compounded the situation.

The LS (RUK) who knew SK's situation before the training but was unable to help, was able to think of several options after her training through VCBR. She identified him as a person with multiple problems such as difficulty in moving, poor communication, total dependence for all day-to-day activities, and lack of security. This boy was tied to a pole and kept inside the house during day when his father was away because children in the neighbourhood would tease him by shouting and throwing stones at him if he was outside.



The LS felt that options for SK's care in the home situation were limited. She brought his case for discussion with the VCBR team. Following extensive discussion within the team and with his father, VCBR organized his admission in a residential home for orphans.

SO

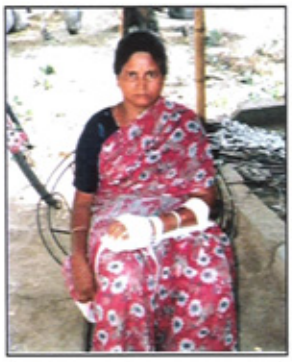
SO is a 45-year-old unmarried man who lives with his widowed mother in a hut. He was a rickshaw puller before he met with a road traffic accident at the age of 20 years. Because of an addiction to alcohol, he was irresponsible and irregular at work. His alcohol addiction was the cause of his accident. Following the accident he was taken to the tertiary care centre (CMC) where he was treated for head injury. After discharge he did not go back to the hospital for follow-up. His mother runs the family on the family pension received from her husband's work place.

During a survey the LS (RP) identified him as a person with difficulty moving. He was walking with the help of a walking stick. She taught him some exercises to improve his mobility. She referred him to a support group for people with brain injury being held at the tertiary care centre. As he was dependent on his mother's pension she suggested that he be reimbursed the cost of his travel for attending the group. He was not happy about the group therapy, as it did not confirm to his expectation.

VI

VI is a 50-year-old widow who lives with her three sons in a remote area. Except her youngest son the others have to go out of station for their work. She was very active and mobile before she had a stroke as a result of undetected hypertension. She had initial treatments at various places including native medicine for the stroke, but she became immobile and dependent for daily activities. So her youngest son had to assist her for her day to day activities. There was also a caring neighbour who visited her regularly and helped her with daily activities, especially bathing and dressing. The family arranged a marriage for VI's elder son with the hope that the daughter-in-law would take care of her. But the daughter-in-law was not prepared to do so and there was a conflict within the family. Some times VI felt hurt by the reactions of her daughter-in-law.

At this point, the LS (MAR) helped to make VI partially independent in self-care activities through a combination of exercises and counselling. The LS has innovatively used a coconut shell as a splint for her deformed hand. For the hypertension, she was offered free care in the secondary care centre. Although she was able to make use of the offer for a short period of in-patient care, she found it difficult to access continuing care because of her physical and financial situation. Because of her difficulty in moving, transport to the secondary care centre and back was beyond her means. However with the help of the LS and the secondary care centre she continued to take the medicines even though regular monitoring of blood pressure was not possible. With time and continuous follow-up by the LS, VI's mobility and confidence improved. She is now able to come for regular monitoring of blood pressure to the secondary care centre.



DH

DH is a 55-year-old man who lives with his wife and a son. His daughters are married and living with their in-laws. He works in a wholesale shop, which sells bananas. In addition to his work in the shop, he was selling bananas on a trolley in the evenings. His wife does some beedi work and his son is employed in a private company in a city. He used to drink alcohol almost every evening and met with a road traffic accident under the influence of alcohol, sustaining a head injury.

He was taken to the tertiary care centre for acute care. After some time, he was transferred to the secondary care centre as he could not afford to pay the hospital expenses. At discharge, he was linked with the VCBR staff and the LS for follow-up. The LS (NE) found that he was having multiple problems such as loss of memory, poor concentration and anger. His wife had a difficult time with him after discharge. One day she rushed to the LS's house in an emotional state because of stress resulting from his behavioural problems. The LS listened to her and counselled her. The LS made several visits and spent time with her. She referred DH and his family to the support group for people with brain injury in the tertiary care centre. This helped to improve his confidence and he was able to go back to work.

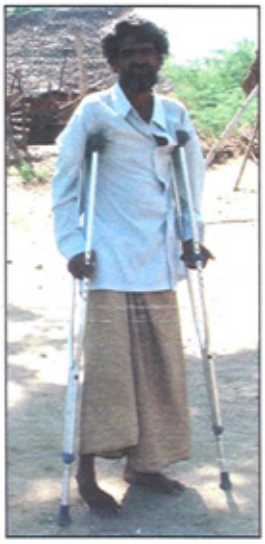
UM

UM is a 3-year-old girl with developmental delay who has been brought up by her grand mother as her parents were unable to care for her. UM had been taken to various centres with the hope that she would be cured. Since there was no improvement in her condition, the family stopped seeking further medical care.

The LS (NE) identified UM as a bedridden child with multiple problems. She visited UM regularly and worked on her sitting balance and neck control. She was able to use the locally available materials for stimulation. She used a broken cane chair as a sitting aid and made a neck collar by using hardboard and cloth. UM's grandmother was cooperative initially but lost hope after some time because she did not perceive dramatic change.

AR

AR is 50-year-old who lives with his wife at Kuppaimedu (means a dumping place). Both husband and wife are rag pickers. They have no children. Although he has post polio residual paralysis, partial blindness and hearing difficulty he was living independently. However over time he became tired, unable to work and bedridden.



The LS (MAR) identified AR during a survey. She felt that she could not help AR in the community because of multiple problems some of which were beyond her capability to handle. She referred him for admission, detailed evaluation and appropriate intervention to the secondary care centre. He was diagnosed to have tuberculosis and malnutrition in addition to his disabilities due to polio and injury. He was helped to get free anti TB drugs through a Government programme (DOTS) and given nutritious food. After he was discharged, the LS made special efforts to make sure he continued his medication regularly. She put him on an exercise programme, which helped to straighten his bent and stiff legs, motivated the neighbours to make wooden parallel bars, where he could practice walking and procured a pair of axillary crutches through VCBR. This collective intervention helped to improve AR's mobility and confidence to such an extent that he was able to take up work as an assistant in a tea stall.

KB

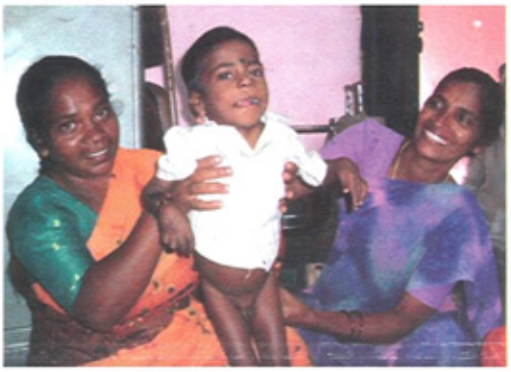
KB is a 25-year-old Muslim girl who completely lost her sight in childhood following an infection. She lives with her aged mother and has been partially independent for most of her day-to-day activities. The source of income for their family is through her mother's beedi work. Although her brother lives next door he is unable to give them financial support since he also lives a hand to mouth existence. KB has two supportive neighbours who are her friends.

The LS (SK) visited her several times and found that KB and her family were not aware of the government schemes for the persons with disabilities. So she took KB to the District Disability Rehabilitation Office, Vellore and arranged for an identity card, which is an important document for availing of any government benefits. With this ID card, KB has applied for and now receives a monthly disability pension of Rs.400/- from the government. This has improved her confidence and status in the family.

KU

KU is a 5-year-old boy with profound developmental delay and has been under treatment at various centres. He has a younger brother who is one year old with the similar problem. KU's parents are very caring. His father works as a painter and mother is a housewife and most of her time is spent for the care of her children.

The LS (RP) identified him as a person with multiple problems and started giving an exercise programme. She also made a neck collar using cardboard for improving his neck control. He was taken to the tertiary care centre whenever he falls ill, but they found that the cost of the care especially for buying medicines was difficult.



VA

VA is a 29-year-old married lady who lives with her husband. They do not have children. Her husband has an alcohol addiction and subjects her to violence. She developed tremors all over the body and found it difficult to walk and carrying weights.

The LS (MJM) identified VA as a person with difficulty in walking and carrying out some of her daily activities. She started teaching her some exercises to improve her standing balance. In the mean time the VCBR team during a community visit suspected she may have a medical reason for her tremors. She was referred to a special clinic (Neuromuscular clinic) conducted by the tertiary care centre and diagnosed to have B12 deficiency. She was advised to have B-12 injection for a long period of time. The LS continued her therapeutic training and also facilitated the treatment at the secondary care centre. But VA was not satisfied with her improvement.

HB

HB is a 34-year-old man who lives with his wife and four children. He worked for a moneylender and his responsibility was loan recovery. In this work he would often threaten and hit people who were defaulters. He used to earn a lot and spend lavishly. He has weakness and restricted movements in left lower and upper limbs following either a head injury or a stroke. Since then his wife is struggling to manage the family by doing the beedi work and he is idle at home.

The LS (MJM) identified HB as a person with difficulty in walking. She started working on improving his mobility. She gave him vocational counselling and informed him about ways to obtain government welfare benefits. But he was not cooperative and was unable to make use of the help.

MU

MU is a 50-year-old man who lives with his wife and two daughters in a slum. Both his daughters are working and taking care of the family. Initially he did beedi work and then worked in a shop as an assistant. He had infected ulcers on the feet due to diabetes and was afraid and uncomfortable about attending the secondary care centre as he had discharged himself against medical advice earlier for some other problem. His wife approached the LS (SK) and sought help for her husband.

The LS visited him and referred him to the secondary care centre for care. He received medical care for diabetes at the secondary care centre and had an amputation of his left lower limb at the tertiary care centre. The secondary care centre involved the LS for his postoperative care especially for dressing of the wound and for regular follow-up. He was given a free prosthesis by the tertiary care centre. With all these interventions, he went back home with improved mobility and control of blood sugars. The LS tried vocational rehabilitation but failed, as he was not motivated.

AN

AN is an 11- year-old boy studying in a government primary school. His parents are daily wage labourers.

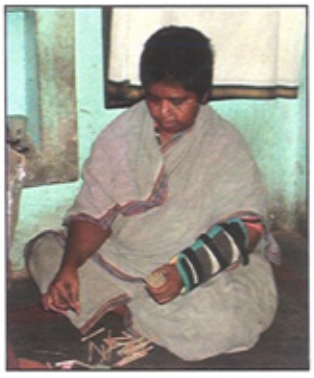
He had difficulty in seeing the black board and headache leading to poor performance in studies. His class teacher identified his difficulty in seeing and referred him to an eye camp. Following screening at the camp, he was referred to the eye hospital for further investigation, diagnosis and treatment He was prescribed spectacles.

As his parents could not afford the spectacles, the LS (MAN) assisted AN to get free spectacles through VCBR. With the spectacles, his eyesight improved and his headache disappeared. Some of his peers teased him when he wore the spectacles and he felt upset about it. There was also a risk of breaking the spectacles while playing. The teacher counselled his friends not to tease AN. She also took special efforts to safeguard the spectacles during his playtime.

DE

DE is 38-year-old lady who got separated from her husband soon after marriage. She lives with her elder sister. The whole family does beedi work for their livelihood.

She had a fall and fractured her upper limb, which affected her daily activities as well as her beedi work. She was taken to a traditional bonesetter for care.



The LS (MAN) identified her as a person with difficulty in using her hand due to pain and stiffness. She started giving an exercise programme, which helped to improve the movements in the hand. During the course of intervention, she had a fall again and fractured the same hand. The LS invited the VCBR team for a visit and she was supplied with a splint for pain management. With the use of splint and the regular exercises, she was able to restart her beedi work and carry out her duties in the home.

APPENDIX 5 – TOPIC GUIDE

The researcher had some common questions and a checklist for conducting interviews with the PWD/Carer/LS. Three phases of individual's life pre disability status, post disability status and post intervention status were covered during the interviews.

Common Questions:

What are the needs and problems of PWD identified?

What are the needs and problems of PWD addressed?

What are the factors related to QOL of PWD?

Did the PWD perceive any changes in various domains of QOL following intervention by CBR?

What are the roles of LS, secondary, tertiary care centres and other sources in improving the QOL of PWD?

Checklist:

Physical

Mobility, Health, Physical activity, Pain, Food intake, Vision, Hearing, Independence (self care), Sleep

Psychological

Happiness, Anger, Behaviour, Memory, Fear, Self-pity, Suicidal thoughts, Concern about future, Avertion, Emotional liability and feelings, Self-confidence, Worries

Social

Family support, Responsibility, Conflict, Domestic violence, Family burden, Family status/respect, Discrimination, Interaction Peers/Friends support, Family functions, Social functions, Political support, Neighbourhood, Social Institutions, Stigma and public attitude

Economic

Income and Expenditure pattern, Savings, Loan, Money management, Economic support system, Cost of rehabilitation

Vocational

Studies/Vocation, Nature and Type of vocation, Home management, Security system, Vocational counselling, Vocational Training, Vocational placement, Government role

Spiritual

Faith, Prayer/Worship, Petition, Visits to Temples/Churches/Mosques, Rites, Celebrations, Devotion, Fasting, Customs and Beliefs

Leisure

Type, nature and significance of leisure activities

Other aspects

Traditional practices, Access to resources, Doctor shopping